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AUTHOR Moore, Judith A.; And Others
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ABSTRACT

The project, Extending Family Resources, was designed to assess the impact on 14 families of raising children with handicapping conditions and to implement a model program to reduce obstacles facing those families. The model emphasized incorporating under-involved relatives, friends, and neighbors into the family's support network. Performance contracts were developed and regularly evaluated, and stipend money was available to help reduce barriers of expenses, time, and skills. Recruitment of family supports was undertaken by the families themselves as well as by project staff. Service plans addressed such needs as respite care, additional home programming, additional equipment, and transportation. Training focused on a variety of topics, including handling and positioning techniques, feeding skills, and behavior management. Data from analysis of family and staff impact revealed that family support systems with a variety of trained participants can reduce stress related to a child's handicapping condition. An analysis of the stipend component is followed by results of a survey of economic, social, and psychological factors contributing to family stress in 448 cases. Stress ratings of the medium income group were frequently as high as or higher than those of the lowest income group. The severity of the child's disability was highly related to the number and severity of the parents' problems. (CL)

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Extending Family Resources

Moore, Judith A., M.A.

Hamerlynck, Leo A., Ed.D.

Barsh, Elizabeth T., M.S.W.

Spieker, Susan, Ph.D.

Jones, Richard R., Ph.D.

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EXTENDING FAMILY RESOURCES
A Project of National Significance

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Judith A. Moore, M.A.
Project Director

Leo A. Hamerlynck, Ed.D.
Primary Consultant

Elizabeth T. Barsh, M.S.W.
Family Clinician

Susan Spieker, Ph.D.
Research Associate and Family Clinician

Richard R. Jones, Ph.D.
Evaluation Consultant

Special acknowledgement is given to:

Joni Jerin
Research Secretary

Lilli Karamanos
Research Assistant

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Children's Clinic and Preschool
Spastic Aid Council, Inc.
1850 Boyer Avenue East
Seattle, Washington 98112

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Chapter I

INTRODUCTION

The Extending Family Resources project was conducted at Children's Clinic and Preschool, operated by the Spastic Aid Council, Inc. in Seattle, Washington. Children's Clinic and Preschool is a private, non-profit agency which serves children with cerebral palsy and other neurological impairments.

Extending Family Resources was funded as a one year "Project of National Significance" by the Administration on Developmental Disabilities, Office of Human Development. However, the points of view expressed in this monograph are solely those of the professionals involved with the Extending Family Resources project.

The project was divided into two goal areas. The first was to assess the social, personal and financial impacts on families who are raising children with handicapping conditions. A survey was developed, distributed and analyzed for that purpose. The second was to implement a model service program to reduce barriers facing a family raising a handicapped child.

The second chapter of this monograph describes the model service project and its results. The fourth chapter describes the family survey and its conclusions. Additionally, the third chapter reviews the use of direct subsidies with families. Monetary payments were made to families as part of the Extending Family Resources service model. Consequently, a review of current trends and practices in other settings is included for the reader's consideration.

This report is directed at a diverse audience including administrators, clinical staff, researchers, academicians and social service personnel. The contents add information to the field of developmental disabilities in both research and clinical areas which can aid in making future administrative and program decisions.

Chapter II

SERVICE MODEL

Brief Description of Project

The Extending Family Resources (EFR) project was a service model designed to reduce barriers to raising a handicapped child and extend the support systems of families with handicapped children. Families were helped to incorporate existing but under-involved relatives, friends and neighbors into the family's support network. For some families, it was necessary to supplement their existing network with community volunteers. Relatives, friends and volunteers were inclusively referred to as "extended family members."

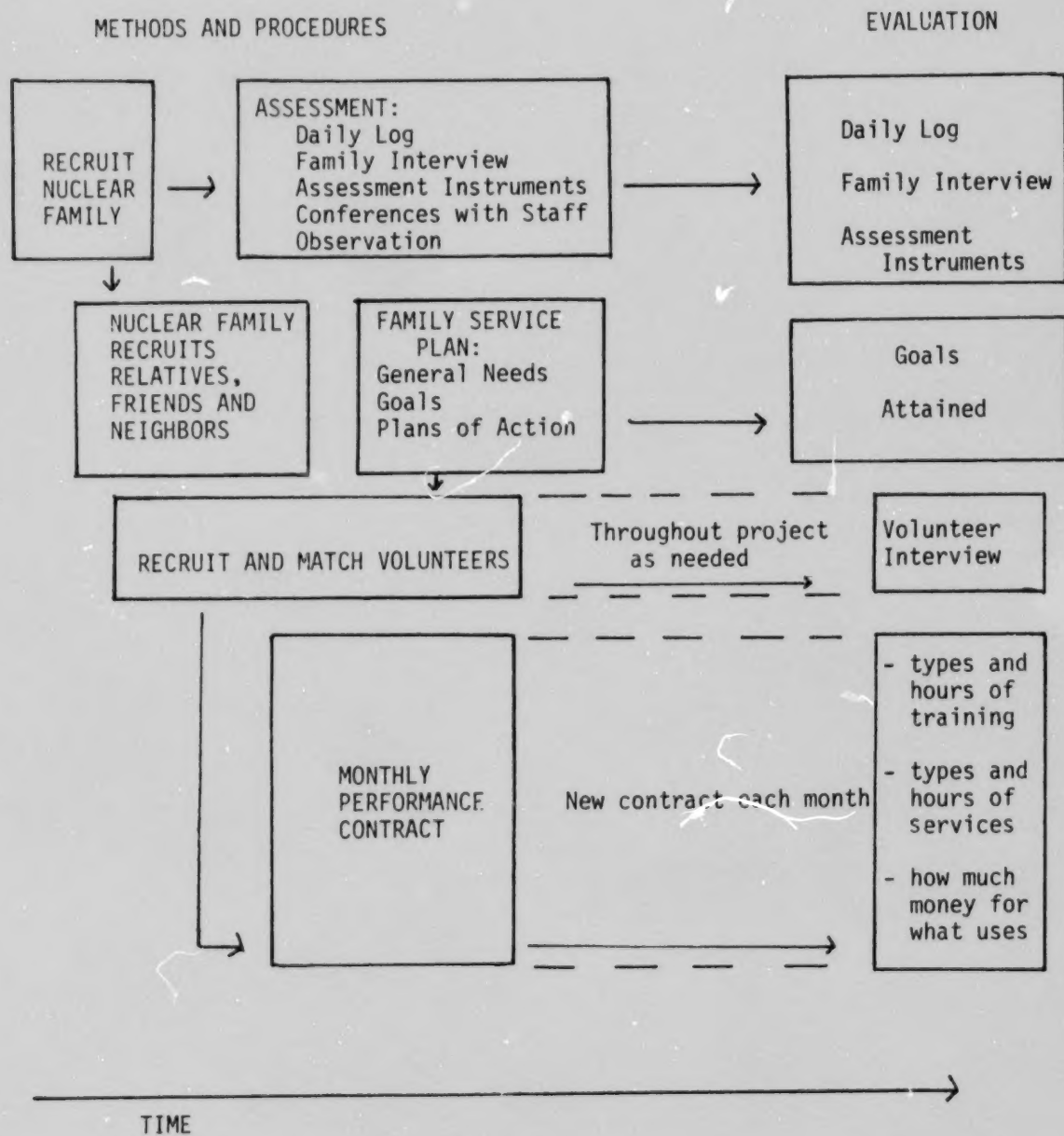
Extending Family Resources was a year long project conducted at Children's Clinic and Preschool in Seattle, Washington. Children's Clinic and Preschool, operated by the Spastic Aid Council, Inc., is a multidisciplinary agency serving young children with cerebral palsy and other neurological impairments. Children receive therapy and education programs; medical and family services are also provided. Participation in EFR was available to any client family, and constituted an additional complementary service for the child and family. Fourteen families were recruited from the Children's Clinic and Preschool population; two additional families in the project received basic services for their children elsewhere, which were then complemented by EFR services.

The framework of the project was applied to all families, while elements within that framework were individualized according to each family's needs. The framework of the project is depicted in Figure 1.

Families were invited to participate in the project. If they agreed, they were urged to recruit other family members, friends and neighbors. The nuclear family was assessed using a Daily Log of the primary caregiver's activities, family interview, measures of social support and special expenses, conferences with treatment staff, and observations. Then the nuclear family and the Family Clinician met to draw up a Family Service Plan, which specified areas of concern, goals and general plans of action. If volunteers were needed, this was specified in the Family Service Plan, and the process of recruiting and matching volunteers to families began.

Monthly Performance Contracts, drawn up in family meetings in the home, translated Family Service Plan goals into detailed steps and activities. The contracts specified who was to do what, when, for how long, and for how much, if any, stipend money. Performance Contracts drawn up in the earlier months of the project listed training sessions that extended family members were to attend, while subsequent Monthly Performance Contracts specified the service tasks, such as respite, programming, and transportation, that extended family members would perform. The extended family and Clinician met at least once a month to review and plan Performance Contracts.

Figure 1
 FRAMEWORK AND BASIC COMPONENTS OF
 EXTENDING FAMILY RESOURCES SERVICE MODEL



Stipend money was available to each family to increase extended family members' involvement with the child and reduce barriers to programming and other services. The family and Clinician decided together how this money would be earned, and this decision was detailed in each Monthly Performance Contract. The use of the stipend was directed toward reducing barriers of expenses, time and skills. Families had available a stipend of \$200 each month, and varied in how and why their money was used.

A variety of evaluation measures was used to assess the impact of the project. The families were interviewed before and after the project, and they completed assessments about their financial situation and social supports. Daily Logs, which measured how much time the primary caregiver was involved in child care and other activities, were collected at the beginning of the project, and for the last six months of the project. Finally, data were collected on the manner in which each family progressed toward meeting its goals. These data included the types and number of hours of services provided, the changes reported by the primary caregiver on her use of social supports, the quality of her daily life, and the use the family made of its stipend money.

Conceptual Background

The Extending Family Resources project operationalized a concept which originated in the experiences of professionals involved in delivering services to handicapped children and their families. In essence, the EFR concept emphasized utilizing the social network of a family to assure that the parents acquired the special skills necessary for parenting their handicapped child, and that they were personally supported and assisted in their efforts by an "extended family," whose members consisted of relatives and family-like friends, neighbors and volunteers.

The general goals of the EFR project were to:

1. Help parents acquire the special knowledge and skills they need to raise and care for their handicapped child.
2. Enable relatives, neighbors and volunteers to learn and practice ways of supporting parents of a handicapped child.
3. Help relatives, neighbors and volunteers acquire the special knowledge and skills they need to provide care for the handicapped child.
4. Extend educational and therapeutic programs for the handicapped child into the home environment through the family network.
5. Facilitate the above goals, and the development of the family's social network, by reducing or eliminating physical, economic, behavioral, and motivational barriers to these activities.

The EFR concept focused on the reciprocal nature of social interactions between extended family members and the nuclear family of the handicapped child. The concept led to the development of procedures to maintain positive, mutually supportive relationships among the members of the extended family. Generally, the procedures centered upon skills and knowledge related to the handicapped child. This background of shared competence and task orientation facilitated the positive nature of the interaction. This rationale was a basic component of all of the EFR project goals listed above. The EFR concept was new and unique in terms of its employment of social support networks to relieve and assist handicapped children and their families. The concept, however, was soundly based on both clinical experience and scientific studies from a variety of disciplines concerned with parent-child relationships.

Historical Development of the EFR Concept

Based on his experiences designing and operating services for families of developmentally disabled children, Hamerlynck first described the EFR concept in 1977 (Hamerlynck, 1977), when he reported that home-visiting parent trainers described their roles as family "aunts" or "grandmothers." Parent trainers found that mothers frequently wanted to talk to them about problems which were unrelated to the handicapped child. Recognition of the need for, and the ameliorating consequences of, the supportive roles of the parent trainer, contributed to the initial proposal to conduct an EFR project.

Following several frustrating attempts to secure funds for a demonstration of the concept, the Foster Extended Family (FEF) project was conducted. The FEF project provided training and other support services to foster families of severely handicapped children--children who would have been placed in an institution if special foster care was not available. This project constituted the pilot study for the EFR project, and the clinical procedures and components of EFR were developed at this time (Hamerlynck, 1980; Hamerlynck & Moore, 1982; Barsh, Moore & Hamerlynck, in press).

In summary, the EFR concept had its roots in the practical experiences of professionals in the human service fields of parent training and early intervention. The EFR concept also had theoretical and empirical roots in a number of disciplines. These range from the fields of stress and coping, family and parenting, early intervention, mental health, and early childhood education. The following section will review the literature relevant to the EFR concept.

Theoretical and Empirical Bases of the EFR Concept

The EFR concept predicts that all of the individuals participating in the project: the handicapped child, the parents and siblings of the child, and the extended family members, would benefit. Support for this idea is presented below, in relation to each of the five EFR project goals.

1. Help the parents acquire the special knowledge and skills they need to raise and care for their handicapped child.

Parents of handicapped children perceive that a lack of information about their children's condition and their lack of appropriate skills, constitute barriers to their providing the best possible care for their children (Brewer & Kakalik, 1979; Tarran, 1981). Much of the emotional distress observed in parents of handicapped children can be accounted for by a lack of information and skills (Matheny & Vernick, 1969). Helping parents acquire information and skills, as well as practical assistance in their child's care, is of major importance in reducing stress related to the handicapped child (Bobath & Finnie, 1970). It is particularly important for parents to acquire behavior management skills that are geared to their developmentally disabled child (Mash, Hamerlynck & Handy, 1976; Mash, Handy & Hamerlynck, 1976; Hamerlynck, 1979).

Once parents have acquired the competence engendered by the acquisition of useful skills and knowledge, they would be more confident and less dependent on others to solve their family's problems. They should gain reasonable hopes and expectations of themselves as parents and as individuals. Finally, they should experience some reduction in emotional stress related to their child's handicap.

2. Enable relatives, neighbors and volunteers to learn and practice ways of supporting parents of a handicapped child.

Social support has a number of benefits. Research has indicated that parents who themselves feel supported are more involved with their children (Barnard & Kelly, 1980). The concept of social support as a moderator of life stress has attracted the attention of medical and mental health practitioners. Social support buffers the impact of stressful life events (such as caring for a disabled child), and reduces the risk of physical illness, depression, and anxiety (Dean & Lin, 1977).

The addition of a child to a household is itself a family life change and a stressful event. This event is even more stressful if the child is handicapped. Parenting a handicapped child demands more emotional and physical adjustments than does parenting a normal child (Holroyd, 1974; Holroyd & McArthur, 1976; Gath, 1977). All such families can be considered to be at risk and especially in need of supportive resources.

Researchers have noted, however, that families of handicapped children tend, in fact, to be socially isolated (Call, 1958; Korn, Chase & Fernandez, 1978). Such families are at risk to fail to develop a network, just when they need it. Therefore, special help and encouragement to develop a network of social support may be needed for families who seem to have withdrawn into themselves in response to a child's handicap. This was a primary focus of the Extending Family Resources project.

Research has shown that families with higher levels of positive social support experience less stress in connection with raising a handicapped child (Nevin & McCubbin, 1979). This evidence substantiates the basic premise of the EFR project: by enhancing a family's support system, the stresses experienced by parents in rearing a handicapped child are buffered.

By supporting the parents, we decrease their physical and emotional vulnerability to stress, and increase their ability to be involved with their child and create a supportive environment for the child's development.

Social relationships can provide both costs and benefits. The frequency of social contacts alone is not an adequate measure of social support (Wahler, 1980). Some families of handicapped children may have a dense extended family social network, and still perceive that their support is inadequate because they cannot rely on extended family members for help with their child or to provide emotional comfort for problems related to their child.

One reason why extended family members may not support the parents of a handicapped child, is that they simply do not know what to do. The Extended Family Resources project was designed to convert any existing family networks into a support network for parents of handicapped children, by helping extended family members learn ways of being supportive with skills for training, managing and working with the child. For families without individuals to utilize in their support networks, the project helped to recruit and train "volunteer extended family members" who also provided the range of supports to the family.

3. Help relatives, neighbors and volunteers acquire the special knowledge and skills they need to provide care for the handicapped child.

The relationships fostered by participation in the EFR project would result in at least two kinds of support for parents: (a) emotional support, and (b) practical support. Extended family members who have the knowledge and skills they need to handle a handicapped child would be able to provide both types of support to families. The child would also benefit by the achievement of this goal. Finally, extended family members themselves would benefit from acquiring and using both social and practical support skills through the EFR project.

One such benefit is the participation in mutually supportive relationships with families of handicapped children (Warren, 1981). Volunteers would have the opportunity for rewarding experiences in which they would receive as well as give. The EFR project would offer a reasonable and valuable role for concerned and caring people. Another benefit is the potential for volunteers to improve their understanding and awareness of developmental disabilities (Blackard & Barsh, 1982b).

The Peace Corps, Vista, and similar programs of service appealed to a significant component of our population. These were people of all ages who wanted to help others in need. "Volunteerism" is the term often used to describe their attitudes and activities; there are many people who are seeking a way to add a qualitative aspect to their lives by helping others. Extending Family Resources would provide the means for the expression of such concern. Because it would not demand the full-time commitment required for an adoption or foster home, it could allow a larger number of

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concerned people to be involved. The roles of foster aunt, uncle, or cousin, have varying demands. They would permit people to be involved as extended family members in accord with their individual skills and availability. Professionals, such as teachers and lawyers, and their families could participate without severe disruption to their careers or busy schedules. The opportunity to accomplish a meaningful task, with reasonable time demands, would provide a general benefit to our society and a specific benefit to the handicapped and their families (Schindler-Rainman & Lippitt, 1977).

4. Extend educational and therapeutic programs for the handicapped child into the home environment through the family network.

One extra demand that parents of special children experience is the need to be active in their children's education and therapy programs. Research has shown that early intervention programs which concentrate on parent involvement are more effective in producing long-term developmental gains (Shearer & Shearer, 1972). Bronfenbrenner (1975) concluded that the most effective programs: (a) begin when the at-risk children are very young; (b) are home-based; (c) stress parent involvement; and (d) encourage reciprocal interaction between mother and child.

Professionals are recognizing the importance of the early experience between child and parent for the child's development. However, in their efforts to facilitate this process, they may forget that the reality of interacting with the handicapped child for 24 hours a day is different from being with the child two-three hours a day (Paul & Beckman-Bell, 1981; Turnbull & Turnbull, 1982). It is often hard for parents to carry out a home training program in addition to all the other demands of caring for their child.

The goals of the EFR project were to support parents in their efforts to incorporate educational and therapeutic activities into home life, and increase the number of individuals capable of doing this by training and educating extended family members. The results of assuring that a handicapped child lives and develops in the most normal environment possible are self-evident. The positive results of early intervention in the home environment have been documented (Barnard & Kelly, 1980; Howard, 1978). If the nuclear family is "normalizing" for a handicapped child, then an extended family would provide a "supernormalizing" environment.

The participation of extended family members of all ages and interests would mean that more "natural teachers" would be interacting with the child than would be the case if only the nuclear family were involved. Extended family members would have their own homes available for care, play, and program activities. Thus a number of natural sites and teachers would be available for generalization of the child's skills, in addition to the usual settings of the child's own home and center-based program (Rose & Gottlieb, 1981). There would be more opportunities for incidental learning by the child (Stokes & Baer, 1977). All of these consequences of the child's

association with a variety of caring people, who could also carry out activities with the child in their own homes, would enhance the child's development while reducing time and effort related to stress in the nuclear family.

5. Facilitate the above goals, and the development of the family's social network, by reducing or eliminating physical, economic, behavioral, and motivational barriers to these activities.

Although each family would experience a unique set of barriers to the accomplishment of the above goals, the types of barriers that commonly exist have been identified by a number of researchers. One way of conceptualizing barriers is in terms of deficiencies in family resources. Resources include family finances, education, and qualities like family adaptability and cohesiveness. Resources also include the personal and psychological strengths of individual family members, such as perceived control and self-esteem. Coping strategies, such as the use of social supports in managing stress, are also family resources. In general, families who have high levels of resources are more able to cope positively with stressor events, such as raising a child with a handicapping condition (McCubbin & Patterson, 1981; Breslau, Staruch & Mortimer, 1982; Korn, et al., 1978; Friedrich, 1979).

The EFR project was designed to help families increase and strengthen their resources through a combination of education, training and support services. Educational and skills training would enable families to increase their understanding of their child's handicapping condition and to cope more effectively with the child's special needs at home. Support services would be provided by a Family Clinician as well as extended family members. Extended family members would provide social support to the parents, exemplified in the concrete services of respite care and child transportation. The Family Clinician, working closely with the nuclear family and extended family members, would provide clinical support services to reduce motivational and behavioral barriers (Hamerlynck, 1979). The Family Clinicians would also help families learn better problem-solving methods, time management, stress management and life planning. The Clinicians would help families develop the social skills needed to manage their support systems. Family Clinicians would focus on positive expectations of change and work to build upon the family's strengths.

The family's financial resources were to be strengthened through a system of family stipends. Stipends were developed for use as an incentive system and were to be contingent upon family members participating in training sessions and supplying services to the child and other family members. As a short-term incentive, the stipends were to be a reinforcer to the family for participation in specific events to benefit the child and family; as a long-term incentive, the stipends were to help each family reduce its barriers to raising their handicapped child. Precedent for support stipends to natural parents was based on the Family Subsidy Program implemented in North Dakota in 1980. Furthermore, research has shown that "parenting salaries," contingent upon the parents' report of cooperation with a social learning-based treatment program, resulted in higher compliance rates and lower attrition rates (Fleischman, 1979).

In conclusion, the Extending Family Resources Project was designed to implement a concept which called for reducing stress in the families of handicapped children by utilizing social networks to provide emotional support and practical assistance related to the care of their handicapped children. The concept was a new and unique synthesis of ideas arising from professional experience and research on children and families. The following sections of this report will detail the methods, results, and implications of the project.

Methods and Procedures

Participation in the Service Model

The Extending Family Resources service model enabled families of developmentally disabled children to develop an active support system--in the form of an "extended family." Extended family members included those relatives (e.g., grandparents, aunts, uncles) as well as those non-relatives (e.g., friends, neighbors, community volunteers) who together participated in the activities of the service model and provided supportive services to the families. Families were selected for participation on the basis of need for services, and interest and willingness to participate.

Recruitment and selection process: the initial interview. Seventeen families, either self-referred or staff-referred, were contacted by telephone and then, if interested, personally interviewed in their homes. The interviews had two purposes: (a) to provide information to the families about the project so they could decide if they would benefit from participating, and (b) to solicit information in order to determine whether the families would benefit. A number of child and family related stress factors were discussed. Information was gathered on how the families typically responded to stress and in what specific ways they felt the project would be beneficial to them. If a family decided to participate, then this initial interview also was used to begin laying the groundwork for the Family Service Plan.

Sixteen of the 17 families interviewed were enthusiastic about the project and decided to participate. Only one family interviewed decided not to participate in the project. In that case, the parents felt that they already had adequate supports and did not need the additional training or financial benefits associated with the project.

A number of issues needed to be addressed during these initial interviews with families. One frequently mentioned reservation related to the project requirement that a minimum of three people outside the nuclear family be involved. Some parents were uncomfortable approaching relatives or friends, and others thought they did not know anyone who would be willing to spend time with their child. They were reassured that if a family could not obtain agreements to participate from at least three extended family members, project staff would recruit volunteers from the community to work with the family. Occasionally, parents were reluctant to accept "strangers" becoming involved with their child. They were reassured that all volunteers would be

carefully screened and trained, and that families would make the final decision on volunteers assigned to them.

Another frequently encountered concern was the amount of time and energy to be devoted to the project. Since these families were already experiencing some degree of stress in meeting their children's needs, they were naturally concerned that their participation in the project not add additional demands. They were concerned about the number, length and location of family meetings. Would the project take too much time out of their already busy schedules? Would the project require changes in the way they usually dealt with their children? As they began to understand the nature and purpose of the project, their reluctance diminished. They were reassured that the project was intended to support them, not make more work for them, and that all meetings and training sessions would be scheduled at their convenience.

Need for services. All of the families were experiencing some degree of stress in relation to their children at the outset of the project. At the extreme, the stresses had reached the point to which one family was considering foster placement for its children; this family was referred to the project by a child welfare agency in the hopes that extensive supportive services could prevent family break-up. Another highly stressed mother had placed her child in foster care. Less stressed families viewed their involvement as a way to prevent future problems by learning to deal with their present situation in better ways.

The most frequently reported stress factors for all families were:

1. Lack of time and energy because of the demands of child care.
2. Lack of adequately trained babysitters.
3. Guilt over not "working" with the child more at home.
4. Frustration with the child's behavioral problems.
5. Worry over the child's medical condition.

Some families were faced with other problems. Seven families were single parent families, with the mother, and in one case the grandmother, as head of household. Unemployment was a problem in four of the families; lay-offs and the difficulty of finding work were stressful experiences for the working as well as the non-working members of the family. Eight of the families were low income, receiving benefits from public assistance, SSI or other government programs.

Characteristics of families. Of the 16 families participating in the EFR service model, three families were able to utilize their own existing network of relatives, friends and neighbors to make up their extended families. These families had a strong commitment to working within their own family groups and objected to the use of volunteers. In contrast, four of the families relied exclusively on volunteers. These were families who either had no relatives or close friends on which to rely, or could not obtain commitments from relatives

or friends. These families were more socially isolated, with no support systems upon which to build. Most (nine) of the families, however, supplemented their existing support networks with the addition of volunteer helpers. In each of these families, volunteers became part of an existing circle of people, all of whom learned new supportive roles in relation to the child and family. Table 1 gives an overview of characteristics of families participating in the project.

Family Supports - Recruitment of Volunteers, Friends and Relatives

There were a total of 84 extended family members participating in the EFR service model for at least three months: 25 relatives, 24 friends, and 35 volunteers. Prior to this project, these people had not been involved with the children. Recruitment of these extended family members took place by two methods--recruitment by the families and recruitment by project staff.

Recruitment by families. All parents were asked to enlist the aid of at least three of their relatives and friends. In many cases, nearby relatives and friends were available but under-utilized. In most cases it was possible to identify and overcome the barriers to their involvement.

Reluctance to ask for help. There were several reasons why many parents were reluctant to ask their friends and neighbors to participate. Parents were afraid others would refuse. Often families did not know how to state their request for help. Sometimes, families felt that relatives and friends should help on their own, without being asked. In any case, parents were often reluctant to leave their child in the care of someone else. The Family Clinicians helped families overcome these hesitations. In almost every instance, once relatives and friends were invited, they decided to participate.

Time. Families often felt their relatives and friends could not participate because of time commitments. Since meeting times and training sessions were scheduled on a family by family basis, it was possible to arrange a convenient schedule to include everyone. Approximately 75% of all meetings associated with the project were held during evening or weekend hours in families' homes.

Resources. Families often expressed concern about the financial drain on their relatives and friends. The training stipends and expense reimbursements were an incentive to those who wished to participate but who could not do so financially.

Skills and knowledge. The most frequently encountered barrier to involvement was relatives and friends not knowing what to do and not understanding the child's handicap. They were anxious that they would do more harm than good. For a severely involved child, this anxiety was justified in that the child's needs required specialized care and handling.

Once it was understood that training was provided in relation to their involvement with the child, the anxiety over "what do I do?" was

Table 1

OVERVIEW OF FAMILIES PARTICIPATING IN SERVICE MODEL

NUCLEAR FAMILY	AGE, SEX & DISABILITY OF CHILD	EXTENDED FAMILY	# OF MONTHS ACTIVE IN SERVICE MODEL	CHARACTERISTICS
#1 Mother Father	2 year old White female; hypotonic/athetoid quadriplegia, micro- cephaly; developmental delays	m. grandparents (2) godparents (2) p. aunt (1) friends of family (3) babysitter (1) Total = 9	10	- middle income - only child - completed project
#2 Mother Father	3 year old Black male; right spastic hemiplegia secondary to a cerebral vascular accident during surgery for congenital heart disease. Seizure disorder well-controlled; developmental delays	p. grandmother (1) p. aunt (1) m. aunt/uncle (2) friends of family (2) volunteers (2) Total = 8	3	- unemployment problems - low income - one non-handicapped sibling - family did not complete project
#3 Mother Father	2½ year old White male; severe spastic athetoid quadriplegia	P. grandparents (2) p. aunt/uncles (5) babysitters (2) volunteers (2) Total = 11	10	- unemployment problems - middle income - one non-handicapped sibling - completed project
#4 Mother Father	3 year old Hispanic male; mixed athetoid spastic quadriplegia cerebral palsy, microcephaly; developmental delays; severe articulation difficulties; seizure disorder	friends of family (2) m. aunt/uncle (2) Total = 5	9	- low income - parents separated - two non-handicapped siblings - completed project

15	#5	Grandmother	18 month old White male; repaired spina bifida; cognitively functioning at age level	volunteers (4) Total = 4	9	- single parent (grandmother) - middle income - only child - completed project
	#6	Mother Father	22 month old Native American male; congenital syndrome; severe hypotonia; severe hearing loss; gastostomy tube; developmental delay	p. grandmother (1) grand aunt (1) friends of family (4) babysitter (1) volunteers (2) Total = 9	10	- low income - unemployment problems - one non-handicapped sibling - completed project
			5 year old Native American female; congenital syndrome; severe hearing loss; behavior problems			
15	#7	Mother Father	2 year old White male; severe mixed athetoid spastic quadriplegia cerebral palsy; cognitive abilities reported to be age appropriate	cousin (1) friends of family (3) volunteers (3)	9	- middle income - one non-handicapped sibling - completed project
	#8	Mother	3 year old White male; hypotonia, developmental delay, dysmorphic features suspicious of a congenital syndrome, congenital heart defect	friends of family (2) volunteers (3) Total = 5	9	- single parent - low income - only child - completed project

Table 1

OVERVIEW OF FAMILIES PARTICIPATING IN SERVICE MODEL

NUCLEAR FAMILY		AGE, SEX & DISABILITY OF CHILD	EXTENDED FAMILY	# OF MONTHS ACTIVE IN SERVICE MODEL	CHARACTERISTICS
#9	Mother Father	2½ year old White female asymmetric spastic quadri- plegia secondary to a traumatic head injury; developmental delay	m. grandparents (2) friends of family (2) volunteers (3) babysitter (1) Total = 8	3	- middle income - one non-handicapped sibling - completed project
#10	Mother Father	11 month old Black female; athetoid quadriplegia, severe growth retardation; microcephaly	m. grandmother (1) m. aunt/uncle (2) volunteers (3) Total = 6	8	- low income - parents separated - two non-handicapped siblings - completed project
#11	Mother	15 month old Black male; acute lymphocytic leukemia, severe spastic quadriplegia, secondary to cardiac arrest; significant developmental delays	m. grandmother (1) m. aunt (1) godmother (1) Total = 3	6	- single parent - low income - one non-handicapped sibling - completed project
#12	Mother Father	3½ year old White female; severe spastic/athetoid quadriplegia; microcephaly; severe developmental delay; visually impaired; severe seizure disorder; severe growth disorder	volunteers (2) Total = 2	3	- middle income - one non-handicapped sibling - family did not complete project

#13 Mother	4 year old Black male; mild ataxia; mild spasticity in lower extremities; behavioral problems, hydrocephalus (shunt), mild to moderate developmental delays	sibling (1) volunteers (3) babysitter (1) Total = 5	9	- single parent - low income - adopted child - two handicapped foster children - completed project
#14 Mother Father	19 month old White male; severe seizure disorder; neurological impairment; hypotonia; severely delayed gross motor and language development	m. grandparents (2) m. aunt (1) volunteers (3) Total = 6	8	- middle income - only child - completed project
#15 Mother Father	6 year old Black male; prosthetic legs and feet, visual problems, learning disabilities 6 year old Black male; prosthetic foot; learning disabilities, hyperactive 8 year old East Indian female; polio paralysis (wears leg brace), hyper- active (on medication) 12 year old East Indian Female; learning disabilities	volunteers (7) Total = 7	10	- adopted children - unemployment problems - mental health problems - middle income - completed project
#16 Mother	3 year old Black female seizure disorder, profound mental retardation, severe spastic athetoid quadri- plegia, central visual impairment, severe hearing loss	volunteers (2) foster parents (2) Total = 4	7	- low income - single parent - one non-handicapped sibling - completed project

eased. A crucial point here is that not all relatives and friends were expected to perform the same functions. Each person had a specific role to fill in relation to the child and was then trained in the skills needed to fulfill that role. This was reassuring to relatives and friends who were overwhelmed by the child's many needs and demands. They were not agreeing to be "all things" to the child, but only to fulfill one part of that child's many needs.

Immediate consequences of involving the extended family. The emotional support parents received when their relatives and friends agreed to participate was significant. Even before any additional services had been provided, parents began to feel a sense of relief, a strong sense of togetherness, and a decrease in isolation.

Jim had been receiving therapy services for nearly three years, yet the only family member well known to the staff was the child's mother. Through this project, the father, the grandparents, aunts and uncles became actively involved in his program.

Karen's father commented when his relatives agreed to participate, "I knew they were supportive, but I didn't know just how much until now."

Danny's mother was pleased that members of her family would be participating and especially that they could be reimbursed for services they provided. "This way," she said, "I won't have to feel guilty about taking advantage of them when they help me take care of Danny."

Recruitment by project staff. Some families needed volunteers in order to develop a support system. Volunteers were recruited to participate in this project through a variety of means: radio and television announcements, newspaper articles, and posters on bulletin boards. A sizeable number of volunteers heard of the project through word of mouth, either from other volunteers or from the families. In addition, many employees of the Boeing Company, the largest private employer in the area, volunteered in this project as a result of an article in the company's newsletter.

Volunteers expressing an interest in the project were personally interviewed to determine their skills, experience and expectations. Volunteers were assigned to families on the basis of matching a volunteer's interests with a family's needs. Some considerations in assigning volunteers to families included geographical location, transportation resources, and time commitments. Once a volunteer was assigned to a family, he or she became part of the extended family along with other relatives or friends participating in the project.

Volunteers had many of the same initial problems as relatives and friends: need for flexible hours; need for expense reimbursements; need for skills and knowledge training. There were additional barriers to involvement more significant for volunteers than for family, friends, and relatives: transportation problems and anxiety over working with handicapped children, especially severely physically involved children.

Matching volunteers and families. Careful attention was paid to any factor which influenced the success of a volunteer-family match. Beyond the obvious factors previously mentioned (geographical location, transportation needs, and time commitments), there were several more subtle factors considered.

A match between the volunteer's interests and the family's needs was crucial. If volunteers were not interested in their assigned roles, drop out was likely. Often volunteers initially expressed interest in one activity, but later could see the value of a different activity. Volunteers learned to see their role in relation to the family and child's total needs. They began to understand how their assistance fit into the total plan.

Some families required help to overcome their initial reluctance to the use of volunteers. Usually once they had met and talked with the volunteer they felt more comfortable. It was sometimes important to pay attention to social or cultural factors, but it was not always necessary to match on these factors. In some cases, it was helpful for families and volunteers to be from the same background. In other cases, it made no difference. Sometimes a shared event enabled families and volunteers from very different backgrounds to get to know one another.

A Tupperware party was a critical incident for one family in establishing a close relationship with a volunteer. Vicki's family was a low income family living in the inner city. The volunteer assigned to work with Vicki was an electrical engineer from another part of town. She and the family were not quite sure this match would be successful. On one of the volunteer's first visits, the family was having a Tupperware party. As the family and volunteer shared this social event together, they got to know and like one another better.

Family Service Plan

A Family Service Plan was prepared for each family participating in the project. This Plan specified the activities and general goals for each family. The Family Service Plan constituted an agreement between the Family and the Clinician. It provided general direction to all participants--family, volunteers, professionals--involved with the extended family.

The Family Service Plan provided a written record of the nature of a family's needs for services. This included:

1. A statement of the problem or barrier impacting the family.
2. A statement of the goal to be achieved.
3. A statement of action to be taken to accomplish the goal.
4. A statement of the method to monitor progress toward the goal.

There were many similarities between the Family Service Plan as used in this project and other individualized plans developed for children, such as the IEP. However, there were two important differences. First of all, the Family Service Plan applied to the family as an entity rather than the child as an individual. The range of problem areas considered in this plan was wider than plans written solely for the child. Secondly, the parents were just as actively involved in implementing the plan as they were in developing it.

Purposes of Family Service Plan. The primary purpose of the Family Service Plan was to summarize family assessment information and relate that information to goals and objectives for the family. The written plan linked problem statements with appropriate goal statements. These goal statements provided direction to the clinical and training activities of the project.

An additional purpose of the Family Service Plan was to involve the family directly and actively in the assessment and planning process. The content of Family Service Plans was determined primarily from the needs expressed by each family. Families were motivated to work on problems that they helped to identify and that they viewed as important to resolve.

The assessment process. Goals and objectives were identified through: (a) parent interviews; (b) assessment instruments and daily log data; (c) observations of parent-child interactions; and (d) consultations with the child's treatment team.

Interviews with parents. Any concern or complaint mentioned by the parents regarding a child's care at home was useful in identifying goals. Did the child wake frequently at night? Did feeding the child consume a large amount of the mother's time? Did the parents worry excessively about the child's seizures? All of the above concerns were translated into the following goals:

1. Provide training in behavior management and develop and implement specific programs to decrease the child's waking at night.
2. Provide training in therapeutic feeding techniques, and nutritional counseling.
3. Provide behavior management skills training and implement programs to reduce the child's crying with other family members.
4. Provide information and reassurance about the cause and treatment of seizure disorders.

Parents often mentioned behavioral problems with a child, but rarely identified training as a possible solution. Generally, the family was too close to the problem to take an objective view. Parents often were not aware of the resources available to them to help them solve the problems or the techniques available to make care of the child easier. In these

instances, the Family Clinician helped parents translate complaints into positive goal statements and trained the family in techniques designed to alleviate the problems.

Assessment instruments and daily log data. Several assessment instruments were also administered to parents to identify problem areas that could be positively affected by the project.

Inventory of Parent's Experiences. This 45 item questionnaire described the support available to parents from professionals, their neighborhood/community, friends, and personal/marital relationships. Parents indicated the number of contacts with individuals and satisfaction with each area of support and with their overall life situations. (Crnic, Ragozin, Greenberg, & Robinson, 1981).

Questionnaire on Resources and Stress-Revised. This instrument (Friedrich, Greenberg & Crnic, 1983) identified sources of stress and coping resources in families.

Special Expenses. This checklist identified expenses related to the child's disability and specified the manner in which they were managed by the family.

Daily Log Data. This information was collected via daily telephone interviews with the primary caregivers for a one week period. This assessment provided parent support data regarding the amount and quality of time spent in child care and other family activities. During the last six months of the project, the data collected on the logs were reduced to two questions in order to evaluate goal attainment.

Observations of parent-child interactions. Direct observation also yielded measures of family training and intervention needs. The parents' responses (or lack of) to their child's behavior were recorded on an observation form while parents and child interacted. The Teaching Scale (Barnard & Eyres, 1979) was most commonly used. From the data collected, specific deficits and excesses in parental behavior were identified.

Observations of Jon with his mother revealed that the mother was subtly suggesting to Jon her expectation that he would cry when she left him. When this information was shared with her, she was able to learn more appropriate behaviors toward Jon.

Observations of Tony and his parents showed their tendency to attend to many of Tony's negative behaviors. With this information, it was possible to develop a more effective behavior management program.

Consultations with the child's treatment teams. Other professionals working with a child were fully acquainted with their child's treatment programs and often identified relevant areas for family training or intervention that might otherwise have been overlooked. Because they were responsible for the

child's treatment programs and knew the child well, they were aware of behaviors that made caring for the child difficult. These professionals were aware of the child who was very irritable, extremely difficult to position, or had a feeding problem, as well as the techniques to deal with these concerns. They also had an opportunity to observe parent-child interactions when parents brought the child to school or therapy. Treatment staff also suggested training programs that were "ready" to be generalized to another setting. Because they followed a child's rate of progress on an on-going basis, they were better able to predict which goals were likely to be transferred successfully to the home.

Adam had successfully learned three manual signs. He was using these signs spontaneously during therapy sessions, and his speech therapist felt he was ready to start using them at home as well. After the family received training in signing and began to use the signs with Adam, there was an increase in his use and acquisition of signs.

Writing the Family Service Plan. The Family Service Plan was determined from the needs identified by (a) the parents, (b) the professionals who worked with the child, and (c) the Family Clinician. In the vast majority of cases, there was general agreement among all participants as to the problems and goals. Sometimes, however, people expressed the same problem in quite different ways. In these cases, it was the Clinician's responsibility to point out commonalities.

There was general agreement among staff working with Susie that her mother spent too much time trying to teach Susie at home. Susie's mother did not view this as a problem; in fact she wanted to learn more things to do at home with Susie! After collecting baseline data information and reviewing it with the Family Clinician, however, Susie's mother was surprised to learn how much time she devoted to Susie. With this realization she set a goal to increase time for herself and time with her husband.

Depending on the particular family situation, the gathering of assessment information took place over a one-to-two week period. This included completion of the assessment forms and collection of the Daily Log data. Once all information was gathered, completion of a Family Service Plan required approximately one hour. Generally, only the parents, not the entire extended family, contributed to its development.

Monthly Performance Contracts

Monthly Performance Contracts were the vehicle for implementing the Family Service Plan. The contracts listed what services would be provided and how the stipends would be used each month. The contracts also provided a formalized system for recording and documenting the actions of all members of the extended family.

Purposes of Performance Contracts. Performance Contracts organized the activities of the family and extended family members. No one individual was overburdened, yet each was contributing to the total service plan for the family. Each member was able to see how their involvement fit into the overall plan. In addition, by specifying each individual's responsibilities, the Performance Contract helped to reduce role confusion among family members.

Performance Contracts responded to changing service needs of a family through monthly review and revision. At regularly scheduled family meetings in the child's home, the entire extended family and the Family Clinician discussed new needs for services. This regular process of planning and review encouraged the family to anticipate future needs and prevent crisis situations. Most importantly for the family plagued by continued crisis, performance contracting brought a sense of order and consistency.

The Andrews family experienced one crisis after another, and never seemed prepared to handle an unexpected situation. To overcome this problem, each Monthly Performance contract outlined an "emergency plan." This included a statement of who could be relied on to help out on last minute notice. As the family and volunteers got to know each other better, the written emergency plan was no longer as necessary.

Format of Performance Contracts. Contracts were written for an individual extended family in conjunction with the Family Clinician for a specified time period. The contracts were agreements between the extended family and the Clinician which specified who was to do what and what they would get in return. The contracts specified the desired goals or outcomes for a given time period and the responsibilities of each party for reaching these goals.

Each task was listed separately on the Performance Contract alongside the name of the family member who was to complete the task. Tasks were written specifically, indicating what was to be done, where, when and how it was to be done. Sometimes more than one person performed the same task. The task was recorded separately for each person, along with his or her scheduled completion time, to avoid confusion. Monetary reimbursements contingent upon completion of the tasks were also recorded.

At the beginning of any Performance Contract time period there was:

1. A specification of tasks to be completed.
2. A specification of who was to complete the tasks.
3. A record of deadlines for task completion.
4. A record of services to be provided.
5. A record of family stipends to be distributed contingent upon completion of specific tasks.
6. An approximate "budget" for the family stipend for the coming month.

At the end of a Performance Contract time period when the contract was formally reviewed, the completed dollar amount was recorded for each task based on the extent of task completion. The continued contact between project staff and families throughout the month provided on-going monitoring. It was possible to troubleshoot or make revisions as needed on an on-going basis. The formal monthly review and planning sessions verified completion of the Performance Contract. Dollar amounts per task were summed for the total family stipend and the contract served as authorization for the preparation of the family's stipend check.

Stipends

Rationale. The primary purpose of the family stipend was to facilitate increased involvement with the child and to reduce barriers to programming. At each family meeting where a Monthly Performance Contract was developed, the Clinician and family jointly determined what child needs were unmet, what could be done to remediate the situation and how to allocate the available funds. While there was an upper limit of \$200 to the dollar amount budgeted for each family monthly, use of the stipend was directed toward reducing the barriers rather than toward spending the specific dollar amount.

Services. Services provided by parents, extended family and/or Clinicians included:

Home programming. Child care that followed a prescribed intervention with the child, and was monitored through data collected by the caregiver (parent or extended family member).

Respite care. Short term child care provided by the extended family members to relieve the parents of child care responsibilities for the handicapped child.

Attendance at family training sessions. Specialized teaching sessions conducted by Clinicians or other staff members on specific topics relating to the children and families, and identified by the Family Service Plans. Sessions were designed to increase families' skills or knowledge about caring for their child.

Babysitting. Child care provided to siblings of the handicapped child by extended family members to enable parents to attend family training sessions or spend time with their handicapped child.

Transportation. Transporting the child and/or parents to appointments or meetings related to the child's treatment program (e.g., family training sessions, clinic or doctor appointments, therapy appointments).

Miscellaneous. Books, adaptive equipment, minor architectural adaptations or other services required to carry out home programs with the child (e.g., chair for feeding program).

Payments. Payments to parents or extended family members were specified in the Performance Contract on an item by item basis. Payments were provided

for (a) services, and (b) expenses. Payments were available for new services that were needed at additional cost and that could not be provided otherwise. The following guidelines were used for upper limits to payments.

Services.

1. Home programming: \$3.50/hour.
2. Respite care in addition to what was publicly available: \$3.50/hour.
3. Family training: \$3.50/hour (plus expenses, see below).
4. Babysitting: \$2.00/hour
5. Transportation: 16¢/mile or out of pocket expense for public transportation.
6. Equipment: variable, depending on cost. Equipment payments were available only after other services had been provided.

Expenses

1. Mileage to and from family training session was provided: 16¢/mile or out of pocket expenses for public transportation.
2. If other expenses were a barrier to providing services, they were paid on an item by item basis, for example: meals, phone calls.

Distribution of checks. Checks were delivered to each family at the end of the month. Parents then distributed payments/reimbursements to the other service providers in the extended family.

The majority of parents were able to manage their stipend money efficiently and fairly. Making the parents responsible for distributing payments allowed for more family control in the planning and management of stipend money and encouraged more cooperation and communication among the family.

Since the family developed the Performance Contract with the Family Clinician, members were aware beforehand of the services and payments to be provided. To ensure that there was no confusion at the end of the month, each family was provided with a list of each person's name and the amount of payment owed for that month. For a few families it was necessary to provide additional assistance in distributing the stipend in the form of providing envelopes with the names and dollar amounts written on them.

Carry over and "savings." In general, stipend payments totalled \$200/month or less. Families could "save" up to \$50/month, and this money could be used for future goals.

Family Training

Training goals and objectives. Training goals and objectives interfaced with the overall project goals: to reduce family stress; to increase family participation and follow-through in the child's programming; and to assure cooperation between the families and the treatment professionals who work with their children. The general training goals were as follows:

1. Increasing understanding of the child's handicapping condition.
 - a) knowledge of normal and exceptional child development
 - b) knowledge of the specific needs, and expectations for the child
 - c) knowledge of the child's relative strengths and weaknesses
 - d) information dealing with grief and other emotional reactions associated with having and working with a child who has exceptional needs.
 - e) knowledge of the child's specific treatment and educational programs including the goals and techniques associated with each
2. Developing the special skills and knowledge needed to raise a child who has a handicapping condition.
 - a) behavior management skills
 - b) home programming skills
 - c) special positioning and handling techniques
 - d) relationships with professionals
 - e) knowledge of community resources
3. Developing other skills related to optimal family functioning and reduced family stress.
 - a) family support systems
 - b) first aid and CPR
 - c) stress management
 - d) communication skills
 - e) other skill areas, as needed

Within these general guidelines, specific training objectives, with specified criteria for accomplishment, were tailored to the needs of each

child and family. Training was provided for all relevant aspects of the child's care and treatment. These included any special medical conditions, the child's individual goals as included in the IEP or ISP, speech and language problems and basic care and handling skills, gross and fine motor movement, play skills, and behavior. A special effort was made to ensure consistency and coordination between the child's school program and the activities carried out by the extended family at home. All family training was conducted in conjunction with other professionals responsible for the child's program.

Training process. The emphasis was on identifying the skills and information for each child and then in helping each individual acquire those skills and information in whatever way was most effective for them. Training programs varied both from individual to individual and from family to family. Project staff first made an assessment of the family's skills, strengths, and abilities vis a vis the child's needs for programming. After the needs assessment was completed, a training program was planned to fill any identified gaps in knowledge or skills. Follow-up probes were conducted to ensure that skills acquired were correctly maintained, as well as to ensure that new needs for knowledge or skills were identified.

Needs assessment. In general, needs assessment proceeded through three steps: identification of global training areas, selection of specific training objectives and tailoring objectives to the individuals being trained. The Family Service Plan identified global training areas and the Monthly Performance Contracts were the vehicle for selection of specific training objectives. Then, within the objectives themselves, alterations and tailoring occurred in order to ensure that the specific skills and information covered were directly relevant to the individuals being trained. Some family members or volunteers assumed particular roles vis a vis the child which required specialized training. For example, a volunteer who regularly transported the child to therapy needed a different set of skills and knowledge than the aunt who provided weekend respite care for the child.

Implementation of training. A number of barriers to participating in training were addressed in this project: locale, travel, time and format.

Locale. In general, training was conducted in family groups with parents, relatives and volunteers being trained together in the child's home. Participants were more likely to attend their own "family meeting" than they were to attend a large "group meeting" of several families.

Travel. When training was conducted at Children's Clinic and Preschool, special travel arrangements were made to ensure each person's attendance. Expense reimbursements for travel to training sessions were available through the family stipends.

Time. Training was offered at times when all or most of the family members could attend. The majority of sessions occurred in the evening or on Saturdays for families who had working members

Format. The training format was individualized to different learning styles. Modeling, direct practice and feedback were the most commonly used training methods. The parents themselves were enlisted as primary trainers, along with project staff and other professionals, in order to utilize the parents' extensive experience with their child. When training was conducted by the professionals who worked with a child, the Family Clinician was responsible for coordinating these training sessions and for assuring that treatment professionals' time was used efficiently.

Training for Janet's family included the use of videotaped segments of her performance in therapy sessions. These sessions were held at the clinic because of the need to use the video equipment. After two sessions, Janet's parents came up with a plan of their own. They would use their stipend money to rent a video tape deck so sessions could be conducted at home. They were even able to locate a rental dealer who gave them a significant discount upon hearing their intended use of the equipment.

Training offered by outside community agencies was also utilized. When schools or other agencies offered courses which were appropriate for the families, and met the needs identified on the Family Service Plan, arrangements were made for the appropriate extended family members to attend.

One couple was in need of family counseling to help them cope with having two handicapped children. They had been seen previously at a private agency but could no longer afford the fees. Since this was a significant area of need, part of their family stipend was used to obtain this service.

First Aid and CPR Training. First Aid and CPR courses were offered three times over the year, so families could choose a convenient time to attend. All participants in the project were expected to complete First Aid and CPR certification.

On-going assessment. During regular contacts with the family the Family Clinician considered upcoming training needs. When the child was ready to move on to a new skill, family training was necessary in order for them to teach the skill. Sometimes acquisition of new skills on the part of the child created a demand for new skills on the part of the family. For example, one child rapidly learned manual signs; his family needed to learn them as well in order to communicate with him. Another child learned to indicate "yes" and "no" and to make choices on his own. This required the family to assume a different role in relation to the child.

The family systems also changed over time. Some members left or for other reasons reduced their involvement. Some members assumed new roles with the child. Any changes in the family systems necessitated new training or in some cases re-training of family members.

All of this pointed to the need for on-going assessment of training needs. The identification of training objectives was not a one time event, but an on-going process. Any number of changes, in the child or family, created a need for new or additional training.

Results

Description of the Families

Sixteen families agreed to participate in the Extending Family Resources project, however two families did not complete the project. There were 27 parents and 20 handicapped children involved; Table 1 gives an overview of the nuclear families participating in the project.

There were a total of 84 extended family members participating for at least three months in the service model: 25 relatives, 24 friends, and 35 volunteers. An additional 31 extended family members were in the project for less than three months. The turnover rate for extended family members was therefore 27%: 39% for relatives and 20% for friends and volunteers. In most cases, the reason for dropping out of the program was unrelated to the project. The most common reasons were moving, returning to school, or changing time commitments.

Barriers Addressed by Family Service Plans

On the basis of Daily Log data and discussions with the Family Clinicians, goals were specified in the Family Service Plans. Table 2 gives an overview of the Family Service Plan goals, training, and services provided for each family in the EFR project. All 16 families in the service model identified respite care as an area of need. This was generally expressed as a need to increase mother's time to herself or as a need to increase time as a couple. Increasing the number of people capable of taking care of the child was also a goal for all families.

Twelve of the families identified additional home programming as an area of need. Seven families asked for help in dealing with their child's behavior. Other families wanted to facilitate their child's development in motor, communication, cognitive and play skills.

Eight families needed additional equipment for their children. Sometimes this equipment was necessary in order for other people to take care of the children (e.g., a corner chair). Some pieces of equipment were used in home programming (e.g., fine motor toys). Adaptations to the home environment were also included. For example, one family had a neighbor build a railing for their front steps, enabling the child to walk down the steps independently.

For six families, transportation was needed in order for the children to receive services. Families needed a break from the weekly, and often daily, routine of driving their children to appointments and services. One family had no means of transportation, and without the help of volunteer drivers the child would not have received a therapy program. Other barriers identified by families were: inadequate communication between family and staff; insufficient time and energy for non-handicapped siblings; inability to cope with household chores; and marital conflict related to having a child with a handicapping condition.

Table 2
OVERVIEW OF FAMILY SERVICE PLAN GOALS, TRAINING, AND SERVICES PROVIDED
FOR EACH FAMILY IN THE EFR PROJECT

Family #	Problems Addressed by Family Service Plans										Types of Training Received By Families										Services Provided by EFR Project						
	Respite	Homemaking	Home Programming/ Play Skills	Equipment	Transportation	Behavior Management	Communication/ Resources	Home Adaptations	Couple Communication	Therapeutic Handling	Feeding	Behavior Management	Play Skills	Child's Communication	Parent Class General Info.	First Aid	CPR	Hours of Training Per Person	Hours of Respite Per Month	Hours of Programming Per Month	Total Round Trips of Transportation	Items of Equip- ment Obtained	Homemaking	Hours of follow- up & Clinical Support			
1	X		X	X		X		X		X	X	X	X	X	X	X	X	16	9	5	9	5		29			
2	X		X	X			X			X			X		X			5	0	0	0	0		3			
3	X		X	X		X	X			X	X	X		X	X	X	X	19	21	10	3	2		17			
4	X		X			X	X					X				X		15	24	5	0	0	X	6			
5	X				X					X			X	X	X	X	X	20	9	19	45	6	X	10			
6	X		X			X		X		X	X	X		X		X	X	25	25	1	0	4		24			
7	X		X	X	X		X			X			X	X	X			6	8	8	33	4		9			
8	X		X			X						X	X	X		X	X	16	28	32	3	3		25			
9	X		X	X	X					X	X		X		X			4	14	10	3	1		3			
10	X			X						X	X					X		7	12	6	27	2		11			
11	X		X				X			X					X			6	39	0	20	2		9			
12	X															X		9	11	11	0	0		4			
13	X		X	X		X	X					X	X					15	30	24	12	5		12			
14	X				X	X	X			X				X		X	X	6	39	3	28	0		6			
15	X	X	X				X					X			X	X		15	32	15	9	4	X	18			
16	X		X	X	X			X		X	X					X		28	0	1	48	4		20			

The following case examples illustrate types of barriers addressed by Family Service Plans.

Brad's mother felt pressured by the demands of driving Brad to school. She felt this interfered with her ability to care for her youngest child. A goal was set to recruit drivers for Brad from among the extended family and to set-up and coordinate a schedule for transportation.

Jon was a severely physically involved child in need of therapeutic positioning and handling. Only his mother knew the proper techniques, since the rest of the family had never been very involved in his programming. The family's use of appropriate techniques was increased by providing training and practice sessions to the entire family.

Brian's grandmother was solely responsible for his care. She lacked friends and relatives who could give her occasional breaks from child care. She was frustrated by the demands of raising a young child the second time around, as she put it. A goal was set to recruit volunteer respite care providers for Brian, to give grandmother more time to herself.

Training Parents and Extended Family Members

The training provided to families reflected both the needs of the children, as assessed in the Family Service Plans, and the programs the children were already receiving through their treatment programs. The type of program, in turn, determined the specific training required for the extended family members.

Training was aimed at achievement of all five of the EFR project goals. For example, training in therapeutic handling and positioning for physically handicapped children would:

1. Help parents acquire knowledge and skills they needed to care for their child. (Goal 1)
2. Help relatives, neighbors and volunteers acquire knowledge and skills to handle the child. (Goal 3)
3. Enable relatives, neighbors and volunteers to support parents by being able to care for the child. (Goal 2)
4. Extend the child's center-based program into the home by using handling and positioning techniques learned from the center-based therapists. (Goal 4)
5. Reduce barriers created by lack of knowledge and skills, that had prevented extended family members from supporting the parents, caring for the child, or working therapeutically with the child. (Goal 5)

Eleven families were provided training in therapeutic handling techniques so that they could use proper positioning and handling throughout their daily activities with the children, and to extend the children's learning throughout the day. Knowledge of these techniques made daily tasks, such as dressing and undressing, much easier to perform with the severely physically involved children.

Jon's family viewed a detailed videotape of his therapist demonstrating how to dress and undress him. Then they practiced techniques with dolls until they were able to carry out all the steps. Finally, they practiced it with Jon. Prior to this training, only Jon's mother knew these techniques.

Danny was a severely physically involved child with few voluntary movements. His family was trained in techniques to decrease his muscle tone. After the training the therapists and teachers noticed a marked decrease in Danny's muscle tone, which they attributed to the family's efforts.

Six families were trained in feeding programs to conduct at home with their children. These included therapeutic feeding techniques as well as programs to teach self-feeding skills to the children. Feeding was a crucial skill for respite care providers; without this skill, the parents were not able to leave the children in the care of others for any length of time.

Vicki's oral-motor involvement made her difficult to feed. Once the family was trained in the proper techniques, it was much easier for them to feed her. Vicki's mother also felt more confident in leaving Vicki with other members of the family, knowing that they could carry out the feeding program.

Allen's family was shown how to use the gastrostomy tube. Their knowledge of this procedure helped them to care for Allen. It also helped decrease any anxiety they had about tube feedings.

After Jim's family was trained in his feeding program, other family members began to take more opportunities to be with him. Previously, the parents could not leave him with anyone else. Now they were even able to go away for a weekend.

Six families received training in behavior management skills to increase appropriate child behaviors and improve parent-child interactions. Specific areas included: improve compliance to directions, increase chore completion, eliminate tantrums, reduce hitting, decrease whining.

Steven's family was shown how to implement a behavior management program to increase Steven's compliance to their directions. The program was an adaptation of the one used at school. Steven's teacher demonstrated the procedures at two home-based sessions; then the Family Clinician conducted follow-up practice sessions with the family.

Eight families were trained in play skills to stimulate learning and to teach appropriate use of toys. Many family members were not aware of what types of play were appropriate for their children. Knowledge of play activities decreased their anxieties about "what to do" with the children and increased their ease and confidence.

Susie's parents noticed a dramatic change in their relatives and friends after several sessions. Now when they came over to visit, they actually played with Susie, instead of ignoring her. All of the family reported feeling more at ease with Susie and able to have more fun with her.

Seven of the families were trained in their children's communication programs, to enable families to be more responsive to the children and to include them more in family activities. This was especially true for children using non-vocal forms of communication, such as signing or communication boards.

Jon was a severely involved child who used non-vocal means of communicating. When his speech therapist showed the family how he looked to indicate choices, one uncle commented "he's just been trained to look to the right." When the uncle realized that Jon really did look to the toy he wanted, his whole attitude towards Jon became more accepting. He no longer viewed him as "retarded" but as a child learning to use an alternative form of communication.

There was an average of 11.5 hours of training for each person in the project, with a range across families of 6 to 28 hours per person. All parents and extended family members were interviewed regarding the training they had received, its quality, and its impact on their lives. Only one couple felt that the training had not affected them in any way. The remaining nuclear families reported positive impacts--including having more skills, feeling calmer, feeling they had better quality time with their child, and feeling more comfortable leaving their child with others.

Most extended family members reported having gained specific skills, knowledge, and understanding (80%) and confidence in taking care of the child (24%). Few (15%) felt that they already had the skills they needed, or did not use the training that was offered.

EFR Services

Table 2 gives an overview of the services received by each family in the EFR project.

Respite. The most significant service provided by extended family members in terms of total number of hours, was respite care. A total of 2,353 hours of respite care was provided to the 16 families who were involved in the project. Across families, the range in monthly respite was 8 to 39 hours.

Programming. The number of hours spent by extended family members in educational and therapeutic program activities with the children was related to the provision of respite care, since the two services were frequently combined. A total of 1,276 hours of programming in specific skills was provided to the children. Eleven children had programs related to physical handling and positioning, six children had feeding programs, nine children had behavior management programs, nine had play skills programs, and eight had communication programs. These figures are a conservative estimate of the amount of programming actually provided, since the training received by the extended family members enabled them to incorporate therapeutic techniques into all aspects of routine care.

Transportation. A total of 240 round trips to medical and therapy appointments were provided by extended family members. Only seven of the 16 families used transportation services, which ranged from a once only trip to Shriner's Hospital in Portland, Oregon, for one family, to twice weekly trips to Children's Clinic and Preschool for another family.

Homemaking. Extended family members performed services in the category of homemaking assistance. One volunteer did mending for several families, and another did some household chores and yardwork.

Equipment. Eleven families obtained special equipment for their children. Equipment was either made by an extended family member, or purchased with stipend money allocated for that purpose in the Performance Contracts. Types of equipment that were made included communication boards, strollers, language books and toys. Types of equipment that were purchased included toys used for programming, tutoring supplies, sign language books, a handicapped parking permit, I.D. bracelets, adapted tables and chairs, railing for stairs, and a play pen.

Clinical Support. Two families received marital counseling from a Family Clinician or counseling professional. Eight mothers received 9 to 20 hours of supportive or vocational counseling from a Family Clinician. All parents received regular follow-up contacts from the Family Clinicians, who also maintained frequent supportive contacts with the extended family members.

Stipends. The average monthly payment to each family was \$149.00. Parents were in turn responsible for distributing the stipend money to the extended family members who had provided services during the month. Table 3 lists the total stipend earned by each family, and the proportion of funds each family allocated for training expenses, equipment and respite. These allocations varied widely from family to family.

Impact of the Project on the Nuclear Family

Goal achievement. The 16 families had identified a total of 75 goals in their Family Service Plans. Of these, 75% were successfully completed, 17% were partially completed, and 8% were not completed. The reasons for not completing the goals were: the family dropped out of the project (37%),

the work on the goal was still on-going at the end of the project (26%), the family failed to follow through on programs for the child (26%), the family did not obtain all the equipment they had wanted (11%).

The evaluation comments of the parents, extended family members, and professional staff all described similar positive effects of the project for the families. These comments will be summarized below in regard to the major results of the project. The assessment instruments completed by the parents confirmed these observations, and are also discussed below.

Respite. The benefit most frequently cited by parents was increased time for themselves. Similarly, the staff members at Children's Clinic and Preschool reported that the project's two major impacts were respite and social support. Respite gave the parents, and in particular, the mother, a break from the demands of child care and additional time to pursue interests of their own.

Programming. Children were exposed to many more adult models as extended family members carried out prescribed therapeutic and educational activities. For many of the children, this socialization experience was an invaluable one. They became more comfortable around other people and in group settings.

The staff evaluations listed several positive consequences for the children. They noted that family members showed increased interest and involvement with the children. Families' involvement enhanced carry over of the children's programs and skills into the home. The most frequently mentioned outcome (7 out of 10 children), although not possible to attribute solely to EFR, was that the children had become more sociable during the course of the project.

Clinical support and stress reduction. Parents were asked whether participating in the EFR project resulted in stress reduction in the nuclear family. Thirteen out of 14 families indicated that the project did reduce stress. The most frequently cited reason for this outcome was that the parents were able to have more time for themselves and each other (10 families). The families mentioned that the fact that their children were helped by the project reduced family stress. One middle income parent stated that, although the project helped her child very much, it did not reduce stress for the parents, because their stress was related to much larger financial problems and limits on opportunities, than they had chosen to address in the EFR project.

Stipends. The "executive function" of parents being responsible for distributing the stipend had a number of positive benefits. Parents reported feeling more in control of planning for their children's needs, and more able to make use of the supports available to them. A number of parents reported feeling less "guilty" about asking their relatives for help, since they could personally and directly reimburse them. This, in turn, made them more willing to let others help. Lastly, for a number of low income single mothers the experience of coordinating and being responsible for "their" extended family contributed directly to increased feelings of self-esteem and personal efficacy.

Parents were interviewed regarding the importance of the money in relation to other elements of the EFR project. Thirteen out of 14 families reported that the money payments were a significant factor in the overall positive impact of the project, but their reasons for why this was so varied. Nine families indicated that equipment and home adaptations were obtained that otherwise would not have been possible. Eight families said that the money made it possible to get services for their children that they otherwise could not have afforded. Six families felt that the stipend money was an incentive for the extended family members' continued involvement with the children. Three families felt that the money was most useful in allowing them to reimburse extended family members for their transportation and child care expenses.

The families unanimously indicated that simply receiving money payments, without the other elements of the EFR project, would not have been as helpful. The families said that the project provided them with the knowledge and skills needed to use the money wisely, and that the families could not have organized and trained the extended family members without the initial advising from the Family Clinicians.

The figures in Table 3 represent how the money was allocated, not the extent to which training and services were actually provided. For example, many extended family members did not actually receive stipend money for training or for services. Instead, they returned the money to the family, with the understanding that the family was going to use the money in some other way to benefit the child, such as on equipment, home adaptations, or other services.

Assessment forms. The assessment forms completed by the parents corroborated information obtained from the final interviews with parents. However, some assessments were either not returned, or returned incomplete. Many items were answered in ways that indicated they had not been understood, limiting the assessments' usefulness in the evaluation of the project.

Inventory of Parents' Experiences. There were eight nuclear families who completed, pre and post, the question on this inventory which asked them to rate their overall current life situation from "very bad" to "very good." Seven out of eight families showed an improvement in this rating from the beginning to the end of the project, and one family maintained the same ("very good") rating. The probability that all of these ratings improved by chance is .008. The data support the conclusion that these families perceived that their overall life situations had improved over the project year.

Questionnaire on Resources and Stress-Revised. Nine families had sufficiently complete data on both the pre and post assessments. Each family received a raw "problem score" in four areas: family and parent problems; pessimism; child characteristics; and incapacitation. The higher the raw score, the more stress a family was assumed to be experiencing. The data were analyzed in terms of how many problem scores decreased from pre to post. Out of 36 problem scores, 24 decreased, 3 remained the same, and 9 increased. The fact that a significant ($p < .05$)

Table 3

ALLOCATION OF STIPEND MONEY BY FAMILIES

Family #	Total Average Monthly Payment	Total Across Project	% Spent For Training	% Spent On Equipment	% Spent On Respite
1	\$165.80	\$1,492.23	31%	40%	14%
2	* 21.00	21.00	100%	0%	0%
3	191.99	1,727.97	22%	7%	41%
4	113.18	905.45	19%	0%	61%
5	146.88	1,468.76	18%	10%	23%
6	181.99	1,455.92	30%	7%	24%
7	111.11	1,000.06	19%	33%	11%
8	185.17	1,666.54	26%	2%	53%
9	96.21	288.64	7%	9%	52%
10	86.57	692.58	13%	24%	44%
11	173.26	1,039.55	11%	15%	70%
12	* 52.58	157.75	28%	0%	72%
13	143.72	1,293.50	13%	23%	53%
14	193.47	1,547.38	4%	0%	92%
15	186.22	1,676.01	18%	6%	55%
16	106.30	744.09	80%	5%	0%

* (did not complete project)

average monthly payment (excluding those who did not complete the project) was \$149.00

number of problem scores decreased supports the conclusion that stress decreased for these nine families.

Special Expenses. Parents were asked to what extent the expenses related to their child's disability affected the overall quality of their family's life. The higher the rating score, the more negative the impact of these special expenses. Nine families completed pre and post ratings. The overall ratings decreased for six families and increased for three. These results are not significant. Unemployment, bad economic conditions, and many fixed expenses related to their child's disability could have affected these results.

Daily Log Data. During the last six months of the project information from each family in two areas was collected--amount of time a service was provided, and the goal to be achieved as a result of the service. The data were recorded in terms of time, for example, as hours of respite and hours of time to self for the primary caregiver. This information was plotted on a graph, resulting in one line indicating hours of service, and another line indicating hours of a goal achievement. A correspondence between the lines indicated that the families were making progress toward meeting their goals. For six families, considerable co-variation existed between the service provided and the goal. These families were achieving their goals. For one family, no co-variation existed. This family was not achieving its goal. One family's graph was unclear. For the remaining families, daily log data were unavailable. (See Appendix A for an example of a Daily Log Graph.)

Impact on Staff

Seventeen evaluations of the impact of the EFR project on their work with the children were completed by Children's Clinic and Preschool staff members. They answered the question: "How has this project either helped or hindered you in your work with the child and family?" Sixteen evaluations reported that the project was quite helpful; one evaluation said that the project was neither helpful nor unhelpful. The evaluations emphasized improved communication with the family and increased involvement by the family, as a result of carry over into the home:

Helped dramatically; I worked more closely with the family, was able to better understand their needs and their perceptions of the child and his communication skills, and the mother followed a home program that was an integral aspect of his communication growth over the semester.

Effective in helping to "hook" the parents into re-bonding with the child.

Impact on Extended Family Members

Fifty extended family members rated four elements of the EFR project in order of their helpfulness. Family meetings and training were considered

most helpful. Forty-two percent of the respondents gave training the first rating; 38% gave family meetings the first rating, 12% rated money payments first; and 8% rated Performance Contracts first.

Extended family members were also asked how the project affected them personally. The most frequently mentioned changes reported by extended family members were increased knowledge (36%), increased understanding and acceptance of handicapping conditions (38%), more skills (20%), more fulfillment (10%), and career related experience (12%). One volunteer decided to go to graduate school in speech therapy as a result of her experiences with the project.

Volunteers also varied in their need for the stipend. Some volunteers could not have participated without the financial support of stipend payments. Others did not feel they needed any payment, or did not wish to accept it. For all volunteers however, the actual value of the services provided exceeded the amount of reimbursement they received.

Peggy was a single parent on welfare. She volunteered to help transport a child to therapy. Even though she was eligible for mileage reimbursements, she refused to accept them, preferring instead to "do this for Ronald all on my own."

Brenda was an out of work special education teacher. She volunteered to tutor children in reading. Even though she was reimbursed for her time working with the children, the hourly rate she received was only a fraction of what she could have received on a private basis. Of the disparity in pay she commented "I don't care; this is what I really wanted to do."

Both the families and extended family members reported that they got along well with each other, with very few exceptions. Reasons for this friendly cooperation varied. Basically, parents and extended family members "got along" when the (a) family members felt the parents were open, appreciated them, or shared some common background or problems, and (b) when the parents felt that extended family members were friends of the family, liked the child, and wanted to be there.

Both families and extended family members pointed out the benefits of the reciprocal and mutually supportive relationships that had developed. With few exceptions, extended family members felt appreciated and needed by parents as part of the "family."

The most frequently mentioned problem reported by extended family members was related to time. Twenty-one persons said that it was difficult to schedule meetings and time with the child because of their schedules. Nevertheless, careful planning ahead with the families made it possible to manage this problem. The parents were increasingly able to handle scheduling arrangements without relying on the Family Clinicians. Eight nuclear families reported no difficulties with their participation in the project. Two said it was hard to contact everyone. One family each reported the problems of: keeping up the momentum, recruiting

volunteers, scheduling times, and enlisting relatives.

When asked what would happen after the end of the project, 38 extended family members said they would probably continue what they had been doing; five said they would not see the child again, three did not know, and two said they would volunteer for another project. Five nuclear families said they did not know, eight said the extended family activities would continue, and one parent said it would be hard for her financially and emotionally.

Conclusions

The evaluation data support a number of conclusions concerning the effectiveness of the Extending Family Resources project and its implications for the design of other programs to support families under stress.

The EFR concept provides for individualized family programs which share a common framework, but account for circumstances which are variable among families, such as income, size, and relatives present or absent.

This synthesis of flexibility and structure was one of the project's key strengths, and an important reason for its effectiveness with many kinds of families. The project generated strategies for reducing stress in both low and middle income families, single parent and two parent families, and families with mildly and severely disabled children. The project was effective whether a nuclear family used familiar persons, volunteers, or a combination of relatives, friends and volunteers in its support network. A consequence of the fact that a basic framework can address the needs of such a diverse population is that individualized family programs can be managed efficiently by a single agency. The importance of an individualized approach to the problems of families with handicapped children is recognized (Turnbull & Turnbull, 1982). The EFR project assures that there is an effective and efficient means for accomplishing this goal.

The EFR project demonstrated that family support systems can and should have a variety of participants.

Relatives, friends and neighbors do not automatically constitute and function as a support network. Sometimes a catalyst, such as the EFR project, is required to foster the reciprocal and mutually helpful relationships that characterize support networks. Once established, however, the very nature of supportive interactions will tend to keep the system operative.

In this project, the extended families were "built" in a variety of ways. Depending on the family group, members were predominantly relatives or friends or volunteers. All family configurations functioned equally as well; differences in the extent to which families reached their goals

were not related to how extended families were constituted. Factors which were important to the construction of a family support system were shared experiences, common aims, and concern for the children. The early months of the project were crucial to the establishment of a smoothly working extended family network. No families dropped out of the project once the critical early period was successfully completed.

The EFR project showed that parents, relatives, friends and volunteers can be trained to work with a handicapped child as an extended family group.

Training was individualized according to the family and the individual, to prepare each participant to perform the tasks he or she was actually planning to do with a particular child. Thus, training resulted in individuals acquiring the skills that they immediately used to work with the children in ways that would not have been possible otherwise. The skills appeared to be as reinforcing as the money earned during training. Extended family members rated training and the family meetings which were the context for training, as the most important elements of the EFR project, suggesting that skills and group membership were as important as the stipends.

The EFR project demonstrated that appropriately trained extended family members can provide a range of support services to families of handicapped children.

Extended family members provided both practical and emotional support to the nuclear family--generally in a simultaneous manner. Respite was a direct support for parents in that it decreased child care demands and responsibilities for the primary caregiver while it increased the parents' time for themselves and as a couple. Transportation and child care for other children also directly supported parents.

Following training the child's relatives increased both the quality and extent of their involvement with the child. This had an indirect effect, in that it increased the parents' feelings of social support and family cohesiveness, and reduced the social isolation of the nuclear families. Sharing home therapeutic and educational programming responsibilities with extended family members relieved the parents and also gave the children opportunities for skills generalization.

The EFR project provided a model for reducing family stress related to a child's handicapping condition.

A number of evaluation measures indicated an overall reduction in family stress by the end of the project. Several factors contributed to stress reduction: the buffering effect of social support; the improved coping strengths of family members as a result of training; and the increased skill on the part of parents in mobilizing and using resources--including their social network--on behalf of themselves and their children.

The EFR project was an effective demonstration of how a child's family-based program can be designed to complement the child's school or center-based program.

Most of the children in this project received their center-based program at Children's Clinic and Preschool. Coordinating the child's center-based and home-based programs was fairly simple in this situation because the EFR project staff and the Children's Clinic and Preschool staff were in daily contact. Nevertheless, a special effort was made to ensure that all professionals involved with a child were informed of and able to contribute to the home program. Despite this increase in their work load, staff members were very enthusiastic about the project, and reported that it helped them in their work with the child. The staff members began to incorporate their understanding of family dynamics and the different people who were able to work with the child, into their program planning.

The EFR project was also able to complement the programs children received from outside agencies. Two families received center-based or school programs elsewhere, and the EFR project staff built cooperative working relationships with some of the professionals from these agencies. This was achieved by maintaining opportunities for open communication and involvement. Those staff from other agencies who became familiar with EFR were enthusiastic about the project. They felt it benefited the children and families, and supported the goals of the children's school or center programs.

The EFR service model demonstrated that the goal of implementing a family support network can usually be completed in a time period of six to ten months.

The EFR project had originally been designed to enroll ten families. However, several families enrolled and graduated from the project according to a time frame that was dictated by naturally occurring events in their lives. For example, a child's transition to a new program precipitated a marked decrease in participation in the project for some families. For this reason, the EFR project was able to include 16 families, rather than 10. It was noted that most families were able to progress through the project in about six to ten months. Knowing that the project duration was finite encouraged families to work hard to achieve their goals within the time allotted. All of the families expressed regret that the project was ending. Some felt that they could have taken more advantage of the project. Families with a lower level of involvement wished at the end of the project that they had been more active.

The EFR project did not solve all of the problems of the participating families during their period of involvement. It provided them with a means of developing and using the resource of social support in their lives. It seemed natural that the families would feel uneasy about continuing on their own, without the organized support of the EFR project. In recognition of this problem, it is recommended that future programs provide families with "booster sessions" at regular intervals after they have graduated from the more structured support of a six to ten month project.

The stipend money was important for removing barriers for families, but its significance was found in combination with other elements of the EFR project.

Money, in combination with the training and support elements of the project, was an important stress reducing factor. Most families did not allocate the whole stipend (\$200) each month. The data collected during the project showed that families needed less than this amount for services for themselves and their child. Besides obtaining services, families also applied a portion of this money for one-time purchases, such as equipment or architectural changes. Both low and middle income families reported that the money made it possible for the primary caregiver to occasionally do something for herself. The money made the difference between severely limited activities and occasional recreation; having time for self was cited by parents as a major reason for reduced stress. This finding is consistent with the literature, which shows that role restriction is a major cause of distress in families and for the primary caregiver (Blackard & Barsh, 1982a; Breslau, Staruch & Mortimer, 1982).

The exercise of their "executive function" in distributing the stipend money was an important benefit for some families. It was an opportunity to learn to manage personal resources in coping with daily stresses.

Reports on the uses of direct payments to families of developmentally disabled persons on South Carolina contribute to an understanding of the results of the stipend payments in the EFR project. South Carolina designed a program of payments to families to prevent financial concerns from causing institutionalization. They found, however, that financial problems related to the disability were not alone the cause for institutionalization. In other words, additional interventions to reduce family stress, such as the EFR project, would be needed to prevent institutionalization.

The role of the Family Clinicians was crucial to the families' successful completion of the program.

Family Clinicians exercised many roles, depending on the needs and goals of a particular family, and were thus another example of individualized programming in the EFR project. Each Clinician was alternatively: a resource coordinator, a family counselor, a parent trainer, a team organizer or a child advocate. The Clinicians had to be knowledgeable and skilled in all these areas, as well as possess flexibility and a good sense of timing in the employment of these interventions. The professional nature of their activities, as well as the fact that they were in positions of authority, and able to issue stipend checks, made it possible for them to organize and mobilize large, inexperienced extended family groups into cohesive support systems for families of handicapped children

Chapter III

REVIEW OF DIRECT SUBSIDIES TO PARENTS

Parents were provided stipends as part of the Extending Family Resources (EFR) project. Because the concept of direct payments to parents is not universally accepted, a review of the use of monetary subsidies to parents is presented. This review includes the EFR project's use of stipends as well as the use by various state governments.

In the EFR project, payments to parents comprise an incentive system. Payment was contingent upon performance of an activity beyond basic care, such as attendance at training sessions to learn skills, or participation in special programming activities for the child at home. Two hundred dollars a month for services for a child was allocated to each extended family according to decisions detailed in the monthly Performance Contract (see page 22). In addition, special money for unusual expenses such as transportation and child care was available while attending training sessions.

The stipends were useful in two ways. As a short-term incentive, they were reinforcers to parents for their participation in training and other activities to benefit their child. As a long-term incentive, stipends helped each family reduce its barriers to raising their handicapped child, by enabling them to purchase goods and services. The Clinician worked with the family to determine these short- and long-term needs. Often families applied their monthly stipend towards a long-term barrier. For example, a portion of the money earned for conducting individual training programs at home each month was "saved" in order to buy a piece of equipment.

The concept of paying parents for activities concerning their own child is not universally accepted. Obstacles to a parent subsidy program include: lack of political momentum for subsidies, belief that paying parents is morally wrong, difficulty with accountability of payments, competition with public programs for money, and the perception that families with handicapped children have too many problems to manage money wisely (Tapper, 1979). Social policy has led more often to the provision of services that substitute for the family, rather than support it (Moroney, 1979). In spite of these factors, there is an increasing trend for states to pay subsidies to families for raising their developmentally disabled family member at home.

A parent subsidy is defined by Tapper (1979) as "a payment to a parent for care provided to the parent's own child; there is no requirement in parent subsidy which states that the parent use the money to purchase services." In England a "Constant Attendance Allowance" is paid as a regular subsidy to all families who care for a qualified individual and there is no need to show receipts of services purchased. Family subsidy programs in the United States do not usually operate in this manner; subsidies are usually given for the acquisition of services. Some variations used by different states are as follows:

Money given for services authorized in an individual program plan.

Stipend money awarded only when previously approved services are documented with records and receipts.

Vouchers or contracts issued to purchase a service.

Monthly subsidies used in combination for basic care and additional services.

Another practice in the use of subsidies is an income means test for the family. Some states use such a test and some do not. There is no income test as part of England's "Constant Attendance Allowance." Indeed, it is felt in Great Britain that as well as financial reimbursement, the allowance is a boost to the family because their extra time and effort in raising their handicapped child is recognized by society.

The following discussion and Table 4 synthesize the most up-to-date information available on subsidy payments to families caring for a developmentally disabled person at home. The information was gathered through a mail and telephone survey of state agencies with responsibility for the developmentally disabled. The subsidy programs are funded by state governments, sometimes contracted to another party. The exception is the state of Idaho, where the program is funded by the Idaho State Council on Developmental Disabilities. The state of Nebraska has had legislation approved for such a program, but has received no appropriation. Literature on family subsidy programs often include information from the states of Washington and Pennsylvania (Bates, 1981; Nebraska, 1980), these two states provide services, but not direct payments. Since the EFR project was interested in the effects of direct payments to parents, only programs in which parents receive payments in cash or voucher are included.

The information was reviewed for trends in how states were using subsidies. Although great variations were found, it appears that the rise in use of family subsidies seems to follow the push for deinstitutionalizing our developmentally disabled population. However, where some states strictly require that the program is for the prevention of institutionalization, others cite deinstitutionalization as a broad underlying concept, and still others provide stipends as a recognition only of the increased costs of raising a handicapped child. Some emphasize that there be a cost-effectiveness component which must be less than the cost of out-of-home placement.

There are some major differences in each state program with no two being the same. Some of the differences are as follows:

Services for children versus services for adults.

General subsidies versus specific services.

Basic care versus specialized services.

Family training provided in conjunction with services versus no provision for family training.

Respite care available outside the subsidy program versus being a part of it.

Use of an income means test versus no financial eligibility requirements.

Eligibility requirements vary among states. For example, the state of Rhode Island includes the mentally ill and long-term hospitalized as well as the mentally retarded and developmentally disabled.

Table 4 indicates whether the program is available statewide and whether it is on a pilot basis or an on-going project. The latest available budget amounts and the most recent number of clients available were used. States have used different funding periods and fiscal years so the most recent information was used versus those of a comparable year. One column indicates whether each program requires an income means test. An abbreviated description of eligibility is provided although many states have very elaborate eligibility requirements. Services obtainable through the programs are not included because the lists are lengthy. In general, most states include those services typically seen as barriers to caring for the developmentally disabled person, including respite care, specialized therapy, transportation, adaptive equipment and architectural remodeling.

Table 4
OVERVIEW OF PROGRAMS PROVIDING SUBSIDIES TO
FAMILIES OF THE DEVELOPMENTALLY DISABLED

State	Program Name	Administrating Agency	Statewide	Pilot	Budget Amount	Number of Clients	Maximum Dollars Per Client	Income Means Test	Abbreviated Eligibility	Other
Connecticut	Parent Deinstitutionalization Subsidy Aid Program	Department of Human Resources	yes	yes	1982-83 \$21,840	17	\$2,000	yes	Physically handicapped or developmentally disabled child with natural parents, not on Public Assistance.	
Florida	Family Placement Program	Developmental Services Program	yes	no	1981-82 \$883,173	1981-82 217	None Must be cost-effective. Average \$30-680 per month.	no	Prevent or return from institution. No age criteria.	Stress use of volunteers, family resources and other agency coordination.
Idaho	In-Home Financial Assistance (there is a respite program in addition)	Bureau of Developmental Disabilities	yes	yes temporary funding	1982 \$45,000 Funded by Idaho State Council on Developmental Disabilities. Proposal to legislature to fund.	Past year 81	\$250 per month or not more than 33% of cost of ICF/MR.	no	Developmentally disabled child (hope to extend to adults) who may be institutionalized.	Average \$420 per family, per year. Had estimated \$6,000 per family but have found families need it most for time limited special needs.
Illinois	Family Assistance Program	Department of Mental Health and Developmental Disabilities	yes	yes	None Used from other budgets when most appropriate placement.	not projected	Maximum equal foster care rate. Approximate maximum \$350 per month.	yes	Family of developmentally disabled person, child or adult. Institutionalized or at risk of institutionalization.	To begin Fall 1982.
Michigan	Family Support Program	Department of Mental Health through four Community Mental Health Agencies	no	no	1980-81 \$650,000 appropriated but reduced by cutbacks.	1980-81 81 in four projects	None	no	Developmentally disabled children at risk of institutionalization.	One program pays general subsidy, other three pay for specific services. More Community Mental Health Boards in state are interested.

State	Program Name	Administrating Agency	Statewide	Pilot	Budget Amount	Number Of Clients	Maximum Dollars Per Client	Income Means Test	Abbreviated Eligibility	Other
Minnesota	MR Family Subsidy Program	Department of Public Welfare, Mental Retardation Division	yes	no	July 82-July 83 \$525,800	187	\$250 Reimbursement for prior authorized services.	no	Mentally retarded children. Potential for out-of-home placement.	Money distributed through counties. Clients selected from statewide waiting list.
Montana	Family Training and Support Services Respite Services	Department of Social and Rehabilitation Services, Developmental Disabilities Division (with private contractors)	yes	no	July 82-July 83 \$1,125,000	600 Some use only a portion of services.	\$125 per year (support), \$360 per year (respite), \$900 per year (training).	no	Developmentally disabled person. Priority given to younger and more severely handicapped.	Budget amount includes funding for family trainers, respite coordinators and other support services.
Nebraska	Disabled Persons and Family Support Act	Department of Public Welfare	—	—	\$500,000 Proposed	—	\$300 per family.	yes	Disabled person.	Appropriations vetoed by Governor.
Nevada	Family Preservation Program	Division of Mental Hygiene/Mental Retardation	yes	no	1982-83 \$110,000	1981-82 60	\$286 per month legislatively. Prorated to serve more clients to \$160 per month.	yes	Profoundly mentally retarded person cared for by a family member.	
N. Dakota	Family Subsidy Program	Human Services Department, Division of Developmental Disabilities	yes	no	1982 \$300,000	currently (9/82) 143	\$15 per week (basic care), \$35 per week (services).	yes	Developmentally disabled child not receiving SSI.	Found most effective in preventing institutionalization.
Rhode Island	Parent Deinstitutionalization Subsidy Aid Program	Division of Retardation	yes	no	1982-83 \$156,000	43	\$25-60 per week for basic care. \$5-15 per week for training.	no	Person who has been or would be institutionalized (mentally retarded, developmentally disabled, mentally ill, long term hospital).	Can be add-on rate for foster parents also. Separate respite program.
S. Carolina	Family Care Program	Department of Mental Retardation	yes	no	approximately \$11,000	avoidance of institution (9) out of institution (2)	\$150 per month. Use only for special needs.	yes	Mentally retarded child or adult.	Program has been for avoidance of institutionalization. New approach will also aid in deinstitutionalization.

Chapter IV
SURVEY FOR PARENTS OF CHILDREN
WITH HANDICAPPING CONDITIONS

The Extending Family Resources (EFR) project had two major objectives: (a) to conduct a survey of parents of children with handicapping conditions to determine what economic, social and psychological factors, related to their child's disability, were perceived as contributing to family stress; and (b) to design and implement a model service program for families of handicapped children, to alleviate some of the negative impacts identified in the survey. The survey and the model service program were concurrent efforts within the EFR project. This section will focus on the survey.

Background

The literature on handicapped children and their families is consistent in concluding that the birth and rearing of a child with a handicap is a life-long stressor event that affects the parents, siblings, and family system itself. Psychologically, the parents have been characterized as feeling reactions such as chronic sorrow, loss of self-esteem, helplessness, shame, and disorganization of personality (Matheny & Vernick, 1969).

Many researchers assert that these psychological and emotional problems observed in parents of handicapped children are essentially normal reactions to a very stressful life event (Tavormina, Boll, Dunn, Luscomb & Taylor, 1981; Hewett, 1976; Barsch, 1968; Matheny & Vernick, 1969; Wikler, Wasow & Hatfield, 1981). The event is stressful because there are numerous exhausting physical demands involved in the task of raising a handicapped child. Professionals who have worked closely with parents of handicapped children believe that emotional support and counseling alone cannot relieve parental distress. What these parents need, first of all, is comprehensible information on their child, and practical assistance in the physical aspects of their child's care (Bobath & Finnie, 1970; Paul & Porter, 1981). Such services would include financial assistance, respite, transportation, and home management help (Nevin & McCubbin, 1979; Brewer & Kakalik, 1979).

Noting that some families do cope, and even thrive, on the problems associated with raising a handicapped child, researchers have attempted to discover the mediating factors that account for some families being more resistant, and some more vulnerable, to stressful life circumstances (Nevin & McCubbin, 1979; Holroyd, 1974; Breslau, Staruch & Mortimer, 1982). The basic conclusion of this research is that a variety of family resources protect a family from adverse consequences of having a disabled child. Resources can be financial, informational, attitudinal, interpersonal, social, public, or religious in nature. Each family employs its resources in its own coping style. In general, families with more financial resources and

strong interpersonal and community support systems, experience less stress in raising their handicapped or high risk child (Nevin & McCubbin, 1979; Barnard & Kelly, 1980; Breslau, Staruch & Mortimer, 1982).

The family member most at risk for experiencing negative levels of stress is the primary caregiver, who assumes most of the burden of caring for the handicapped child and obtaining outside treatment for the child. Many services and interventions are available for handicapped children. These services can be very beneficial to the child, but they do not necessarily relieve the practical demands on the primary caregiver. In fact, providing transportation to therapy sessions, waiting in doctors' offices, and seeking an appropriate educational setting for a handicapped child, can be very stressful and time consuming tasks (McAndrew, 1976). The primary caregiver is more likely to cope successfully, however, if she perceives that her marital relationship is strong and supportive (Friedrich, 1979), if she has enough education to procure flexible employment, and if she is financially secure (Breslau, Staruch & Mortimer, 1982; Breslau, Salkever & Staruch, 1982). In other words, mothers of handicapped children cope more effectively with their situation if their resources enable them to feel that they have a life of their own, beyond providing care for their child.

Social policy decisions cannot address the needs of handicapped children without considering the needs of their families as a whole. Families are the primary context of handicapped children's early development. If the family is experiencing extreme stress, the child could be negatively affected. The higher incidence of child accidents, abuse, and failure-to-thrive in very stressed, low social-support families is an extreme case in point (Newberger, Reed, Daniel, Hyde & Kotelchuck, 1977). The purpose of the present survey was to focus and define the kinds of problems, and the levels of social, emotional and financial distress, that are being experienced by families with young handicapped children, who are utilizing services currently available in the state of Washington. Identifying problems at the family level is the first step in designing an intervention, such as the Extending Family Resources project, which would benefit the handicapped child by assisting the handicapped child's family.

The design and content of this survey were based on the findings summarized above, reported in the current literature on families with handicapped children, and pilot interviews with parents of children attending Children's Clinic and Preschool. Four basic questions were addressed by the survey:

1. What demographic and child characteristics are associated with families reporting low and high levels of stress related to having a handicapped child?
2. To what extent do families experience hardships because of the actual physical and financial demands of caring for their handicapped children?

3. To what extent do families experience social and emotional distress as a result of having and caring for a handicapped child?
4. Do parents have complaints regarding the availability of services? How does the use or non-use of services relate to the parents' reports of financial problems, physical care demands, and emotional distress?

Methods and Procedures

Instruments

Survey. The survey instrument (Appendix B) contained 75 statements grouped into 10 content categories. The categories were:

1. Finances
2. Obtaining Information
3. Communicating with Professionals
4. Eligibility
5. Availability of Services
6. Community Attitudes
7. Time
8. Impact on Primary Caregiver
9. Limits on Lifestyle or Life Choices
10. Impact on Family

Respondents read each statement and circled a number from 1 ("This situation is little or no problem") through 5 ("This situation is an enormous problem") to best describe how the situation in the statement applied to the family. Respondents could also circle NA ("This situation is not applicable to me or my family"), and were given the opportunity to write in additional comments at the end of each content category.

Background information. Respondents provided information on their family's composition, the disabled child's age and sex, the number and severity of the child's handicapping conditions, services the child received, and the parent's education, income, residence local, and degree of religious involvement.

Distribution. The survey packets were distributed to 1314 families in the state of Washington, through the cooperation of 23 early childhood intervention programs. The agencies distributed the survey packets with

a letter of endorsement and a stamped, pre-addressed return envelope, to their current and recently graduated client populations. Since these agencies primarily served infant and preschool age children, data was gathered predominantly from families with young handicapped children.

Data Reduction

Demographics. Parents rated the severity (1 to 3) of their child's condition in each of six disability areas: (a) large muscle, (b) fine muscle, (c) language, (d) sensory, (e) learning, and (f) behavior. The ratings were summed to obtain a Disability Score ranging from 0 to 18 for each child. The higher the Disability Score, the more severe was the child's disability. Parents also indicated whether or not their child received the following services: (a) physical therapy, (b) occupational therapy, (c) nursing, (d) speech therapy, (e) physician (f) special education, or (g) behavior management or counseling. The number of services per child was summed, giving each child a total Services Score.

Survey categories. Seventy of the survey items were reorganized into seven content categories that were rationally cohesive and contained at least seven items for scoring purposes. Four statements were included in more than one category because they had content appropriate to more than one category. For example, the statement "I cannot afford enough child/respite care to get a break as often as I would like" was included in the Finances category and the Role Demands on Primary Caregiver category.

The seven survey categories were:

1. Finances. Items in this category described a range of financial problems, such as not being able to afford therapy, fear of losing insurance coverage, and worry about future financial responsibilities. (13 statements)
2. Obtaining Information. These items referred to problems finding information on services for one's child, on evaluating what programs were appropriate for one's child, and on learning to provide special care at home for one's child. (10 statements)
3. Availability of Services. These items described the problems that can be encountered in obtaining services for one's child, such as geographic distance, insufficient quantity, poor quality, inappropriateness, or unavailability. (10 statements)
4. Emotional Impact on Primary Caregiver. These items described emotional distress the primary caregiver might feel in relation to her child, such as feelings of powerlessness, depression, and worry about her ability to care for the child. (9 statements)
5. Role Demands on Primary Caregiver. These items reflected the actual physical and time demands of caring for a handicapped child, and whether the caregiver perceived these demands as restricting other aspects of her life. (10 statements)

6. Impact on Family. These items described the effect of the child on the family as a social system. Included here were statements about the marital relationship, siblings, and other relatives, and possible limits on lifestyle or life choices. (15 statements)

7. Concern for Child. These items described basic concerns parents may have for the child's social and emotional development, and future place in the community. (7 statements)

Scoring. Two scores were computed for individual survey items: a Stress Rating and a Problem Score. These scores were also computed for each of the seven content categories, and for the survey as a whole. For some analyses, families were assigned to a Low Impact or High Impact group, depending on whether their Stress Rating for a particular category was below or above the sample mean.

Stress Ratings consisted of a number rating, from 0 to 5, that respondents gave to each survey statement. Average Stress Ratings were compiled for each category as follows:

$$\text{Category Average Stress Rating} = \frac{\text{sum of category statement stress ratings}}{\text{number of statements in the category}}$$

Problem Scores were computed by collapsing the 0 to 5 Stress Rating for each survey statement into a dichotomy, best described as "no problem" versus "yes, a problem." Table 5 describes the derivation of the Problem Score.

The Problem Scores for the categories, and the survey as a whole, were proportions computed as follows:

$$\text{Problem Score} = \frac{\text{number of statements in a category marked "a problem"}}{\text{total number of statements in the category}}$$

The purpose of this dichotomization was to eliminate the highly skewed response distributions due to the fact that relatively few respondents rated the items as very serious problems.

Low Impact Groups and High Impact Groups were determined on the basis of the average Stress Rating for a given category. All families with Stress Ratings below the sample mean were assigned to the Low Impact Group, and all families with an above average Stress Rating were assigned to the High Impact Group, for each category.

Two Representative Survey Items were selected from each of the content categories for further analyses. Only two statements from each category were selected in order to avoid redundancy in reporting the results, as all survey items were intercorrelated. The two items in each category with the greatest amount of "spread" in the distribution of Stress Ratings

Table 5
COLLAPSING STRESS RATINGS INTO THE
PROBLEM SCORE DICHOTOMY

NA = "This situation is not applicable to me or my family."

1 = "This situation is little or no problem."

2 = "This situation is somewhat of a problem."

3 = "This situation is a rather important problem."

4 = "This situation is a very substantial problem."

5 = "This situation is an enormous problem."

NA + 1 = "No problem"

2 + 3 + 4 + 5 = "Yes, a problem"

were generally those that were selected to be representative statements. The only exception to this rule was if the two statements were very similar in content, then the item with the next best rating distribution was selected. Table 6 shows the 14 representative statements, and the distribution of respondents who gave the statement each possible Stress Rating.

Data Analysis

The thrust of the analyses was to determine the general incidence and severity of various problems, and seek correlates of stress for subgroups of families classified by various demographic characteristics. When both the survey data and demographic data were categorical (which was usually the case), crosstabulations were performed to determine if relationships existed. Otherwise Pearson product-moment correlations between scores on demographic variables and scores on survey variables were performed to determine whether a significant relationship existed between them.

Results

The Sample Characteristics

A total of 448 usable surveys were returned within the time limit for data analysis, for a return rate of 34%. The great majority of survey packets were completed by the mother in the family (86%). Most families were natural (91%), two parent (85%) families. In 28%, the handicapped child was the only child, in 34% there was one other child, and in the remaining 38% there were two or more other children.

The median income level for these families was about \$20,000, which corresponds to the 1981 census figures for Seattle. Income level had the following distribution: 21% less than \$10,000; 31% between \$10,000 and \$19,999; 25% between \$20,000 and \$29,999 and 18% over \$30,000.

In two parent families, 14% of the mothers were employed full-time, 19% were employed part-time, 7% said they were "unemployed and looking," 59% that they were "unemployed, not looking." Of the fathers in the sample, 69% were employed full-time, 3% part-time, 8% were unemployed and looking, and 6% were unemployed and not looking (data was not available for 14% of the fathers; for those families only data on the single mother were available).

Single mothers were employed full-time in 19% of the cases, part-time in 14% of the cases, unemployed and looking in 15% of the cases, and unemployed and not looking in 51% of the cases. The difference in employment status between married and single mothers was not significant.

The sample was generally well educated. Only 9% of the mothers and 11% of the fathers reported having less than a high school education. Thirty-four percent of the fathers and 24% of the mothers were college graduates. Twenty-six percent of the families lived in rural areas, 40% in urban areas, and 34% in towns and suburban areas. Thirty-five percent reported that they

Table 6

TYPICAL STATEMENTS FROM SURVEY CATEGORIES
AND DISTRIBUTION OF STRESS RATINGS

	Stress Rating					
	NA	1	2	3	4	5
<u>Finances</u>						
1) "I cannot afford the special therapy my child needs."	27	30	13	9	8	13
2) "I cannot afford enough child/respite care to get a break as often as I would like."	37	28	13	7	5	10
<u>Obtaining Information</u>						
3) "It has been difficult to obtain information on what services are available to my child."	14	40	16	13	9	8
4) "I need information on how to handle and care for my child at home."	34	38	12	8	4	4
<u>Availability of Services</u>						
5) "The services that I would like for my child are located a long distance from where I live."	31	32	11	9	5	11
6) "Because our income is above a certain level, we are not eligible for certain services that we really do need."	35	25	10	8	6	15
<u>Emotional Impact on Primary Caregiver</u>						
7) "Because of the demands of caring for a handicapped child, I have little emotional energy to deal with other areas of my life."	24	32	17	12	7	8
8) "Sometimes I feel powerless to help my child."	18	26	16	13	10	17
<u>Role Demands on Primary Caregiver</u>						
9) "It takes so much time to care for my child that I have little or no time for myself."	20	33	22	9	8	9
10) "One hard thing to accept about raising a child with a developmental disability is that I will be doing certain caretaking tasks for much longer than I had expected."	15	25	19	17	11	12
<u>Impact on Family</u>						
11) "The fact that my child has a handicapping condition has strained my marriage."	32	35	13	8	6	6
12) "My lifestyle is different from what I expected it would be because my child has a handicapping condition."	24	30	17	16	7	8
<u>Concern for Child</u>						
13) "I am concerned that my child might have difficulty developing self-confidence and self-esteem."	19	29	17	16	8	10
14) "I worry that I tend to over protect my handicapped child."	15	32	23	15	7	7

were "not at all involved," 36% said they were "somewhat involved," and 26% said they were "very involved," in a religious organization.

Fifty-three percent of the disabled children were male, and 46% were female. They ranged in age from 4 months to 32 years, although 90% of the children were aged 6 and under. The median age was just under 3 years. The Disability Scores ranged from 0 to 18. A third of the sample scored under 6, another third from 6 to 10, and the remaining third scored 10 and above.¹

In general, this population of children had more neuro-muscular handicaps (83%) than sensory (blindness, deafness) handicaps (44%). Some level of learning difficulty was experienced by 76% of the children.

The Service Scores ranged from 0 to 7. The mean Service Score was 3. The Service Score was positively correlated with the child's Disability Score ($r = .31$ $p < .001$).

Parents reported the services their children received as follows: 40% of the children received the services of a physician; 70% received physical or occupational therapy; 64% received speech therapy; 62% received a special education program; and 9% behavior management or counseling.

Survey Findings

Content Categories. Table 7 shows the average Problem Score for content categories and the total survey.

In general, parents of the more severely disabled children had higher Problem Scores. The Disability Scores were positively correlated with the Problem Scores of all content categories. Table 8 lists these correlations.

The average Stress Ratings for each category and for the total survey, were generally low. Table 9 lists the average Stress Ratings and standard deviations for the content categories. The means were low in part because of the large percentage of NA's (not applicable = 0) for each statement (across items, 15 to 70% of the respondents marked "NA"; on the average, 35% of the respondents indicated "NA" on any one item).

The child's Disability Score was also positively correlated with the Stress Rating in each content category. Table 10 lists the correlations between average Stress Ratings and Disability Scores, for content categories and the total survey.

¹The method of summing disability scores could produce a misrepresentation of those children having low scores. These children might not all have only mild disabilities. For instance, a child with mild ("1") ratings in three areas would receive the same score as a child having a severe rating ("3") in one area. Nevertheless, this scoring system would include only severely disabled children in the upper range of scores, and was used despite its flaws for this reason.

Table 7
AVERAGE PROBLEM SCORES FOR CONTENT CATEGORIES
AND TOTAL SURVEY

<u>Category</u>	<u>Problem Score</u>	<u>S.D.</u>
Finances	.32	.26
Obtaining Information	.33	.28
Availability of Services	.27	.24
Impact on Family	.25	.23
Emotional Impact on Caregiver	.40	.31
Role Demands on Caregiver	.38	.31
Concerns for Child	.42	.31
 Total Survey	 .32	 .21
(N=448)		

Table 8
CORRELATIONS BETWEEN DISABILITY SCORES AND PROBLEM SCORES,
FOR CONTENT CATEGORIES AND TOTAL SURVEY

<u>Category</u>	<u>Correlations</u>
Finances	.35 *
Obtaining Information	.28 *
Availability of Services	.26 *
Impact on Family	.48 *
Emotional Impact on Caregiver	.41 *
Role Demands on Caregiver	.45 *
Concerns for Child	.23 *
 Total Survey	 .45 *
(* $p < .001$)	
(N=448)	

Table 9
AVERAGE STRESS RATINGS FOR CONTENT CATEGORIES
AND TOTAL SURVEY

<u>Category</u>	<u>Average Stress Rating</u>	<u>S.D.</u>
Finances	1.34	.97
Obtaining Information	1.43	.93
Availability of Services	1.27	.92
Impact on Family	1.12	.81
Emotional Impact on Caregiver	1.61	1.08
Role Demands on Caregiver	1.51	1.03
Concerns for Child	1.66	1.08
 Total Survey	 1.37	 .79

Table 10
CORRELATIONS BETWEEN DISABILITY SCORES AND AVERAGE STRESS
RATINGS, FOR CONTENT CATEGORIES AND TOTAL SURVEY

<u>Category</u>	<u>Correlations</u>
Finances	.41 *
Obtaining Information	.33 *
Availability of Services	.27 *
Impact on Family	.48 *
Emotional Impact on Caregiver	.46 *
Role Demands on Caregiver	.48 *
Concern for Child	.28 *
 Total Survey	 .48 *
(* $p < .001$)	
(N=448)	

For each category, crosstabulations between Impact Group (Low or High) and selected demographic variables were performed. The chi-square statistic was used to test for significance.

When Impact Group for the total survey was crosstabulated by income, (Low = less than \$10,000; Low Medium = \$10,000 to \$19,000; Medium = \$20,000 to \$29,999; High = \$30,000 plus), the results showed that fewer High income families were in the High Impact Group. This finding, however, was not significant (chi-square = 6.74, 3df, $p = .08$).

When the individual survey categories were examined, this association between income and Impact Group was significant in two areas: Finances (chi-square = 9.72, 3df, $p = .02$) and Obtaining Information (chi-square = 11.21, 3df, $p = .01$). In general, High income was associated with Low Impact and Low income was related to High Impact for these two categories. Interestingly, this relationship was reversed for the two middle income levels, so that Low Medium income was associated with Low Impact and Medium income was associated with High Impact.

When the Impact Groups for the total survey were crosstabulated by the mother's level of education (less than high school; high school graduate; some college; college graduate or more), more high school graduates than expected were in the Low Impact Group, and more mothers with at least some college were in the High Impact Group (chi-square = 8.83; 3df; $p = .03$). When the individual survey categories were examined for this relationship, it was observed in Impact on the Family (chi-square = 12.29; df = 3, $p = .01$).

One other finding from this level of analysis was that, compared with two parent families, fewer single parents than would be expected by chance were in the High Impact Group for the Availability of Service category (chi-square = 4.36; df = 1, $p = .04$).

Individual Survey Items. Each of the 14 representative survey statements was crosstabulated by those demographic variables that had been significantly related to content category of which it was a member. Some of these items were also crosstabulated with other demographic variables when a relationship was hypothesized based on the literature. The dichotomized rating scheme (0 for "no problem" and 1 for "yes, a problem") was used in these crosstabulations. When further information was required to explain significant results, crosstabulations for the original (6 point) ratings were also computed. Again, the chi-square statistic was used to test significance. In general, analyses for individual items followed the same patterns observed for data analyzed for the categories and the overall survey.

I cannot afford the special therapy my child needs.

Affording therapy was a problem for 44% of the sample. Families with High incomes (\$30,000) were significantly less likely to rate this area a problem (25%; chi-square = 13.00; df = 3, $p < .01$). The lower the income

level the higher the Stress Rating this statement was given (chi-square = 47.04; df = 15; $p = .00$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .19$; $p < .01$).

I cannot afford enough child/respite care to
get a break as often as I would like.

Affording enough respite care was a problem for 36% of the sample but only 17% of the High income group rated respite a problem (chi-square = 22.6; 3df; $p = .00$). The lower the income the higher the Stress Rating was likely to be (chi-square = 33.86; 15df; $p < .00$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .34$; $p < .01$).

It has been difficult to obtain information
on what services are available to my child.

Problems obtaining information on services were distributed throughout the sample: 46% of respondents had some level of difficulty. Mothers employed full-time gave this problem higher overall Stress Ratings (chi-square = 24.90; 15 df, $p < .05$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .16$; $p < .01$).

I need information on how to handle and care for my child at home.

The High income group was least likely to indicate needing information of this nature (15%). The Medium income group was most likely to indicate needing information (35.7%; chi-square = 13.92; 3df; $p < .00$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .29$; $p < .01$).

The services I would like for my child are
located a long distance from where I live.

The ratings on this statement were crosstabulated by location (country, town, city). Not surprisingly, those in rural areas were most likely to have services located a long distance from where they lived. Forty-six percent of families in rural areas said this was a problem, compared to 28% of urban families (chi-square = 10.63; 2df; $p < .00$). In addition, 32% of those rural families who had this problem rated it "enormous," compared to 20% of urban families. Stress Ratings on this item were significantly correlated with Disability Scores ($r = .18$; $p < .01$).

Because our income is above a certain level, we
are not eligible for services we really do need.

Thirty-eight percent of the sample said they had this problem, but the highest group proportion was in the Medium income group (50%; chi-square = 18.42; 3df; $p < .00$). This income group also gave this problem significantly higher Stress Ratings (chi-square = 50.42; 15df; $p < .00$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .19$; $p < .01$).

Because of the demands of caring for a handicapped child, I have little emotional energy to deal with other areas of my life.

As in the statement above, mothers with at least some college tended to say they had this problem more frequently than mothers with high school or less 51% versus 34%; chi-square = 12.28; 3df; $p < .01$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .42$; $p < .01$).

Sometimes I feel powerless to help my child.

More mothers with at least some college rated this item a problem for them (chi-square = 7.22; 3df; $p < .07$). The crosstabulations using the full (0-5) rating scheme did not clarify this finding, as there was no clearcut pattern of relations between Stress Ratings and education level. However, mothers with high school educations or less were more likely to say that no problem existed in this area (chi-square = 25.6; 15df; $p = .04$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .38$; $p < .01$).

It takes so much time to care for my child that I have little or no time for myself.

Forty-seven percent of the sample indicated this was a problem. When the Stress Ratings given this problem were crosstabulated by income level, there was a pattern of results which indicated that the lower the income, the more likely that a greater proportion of the ratings would be higher than the expected value (chi-square = 24.29; 15df; $p < .06$). Seventeen percent of families with Low incomes rated this problem "enormous," compared with 3% of families with High incomes. Stress Ratings on this item were significantly correlated with Disability Scores ($r = .40$; $p < .01$).

One hard thing about raising a child with a developmental disability is that I will be doing certain caretaking tasks much longer than I had expected.

Significantly more families in the Medium income group (70%) than expected by chance (60%) rated this statement a problem (chi-square = 8.17; 3df; $p = .04$). This income group also gave this problem higher Stress Ratings (chi-square = 28.21; 15df; $p < .02$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .50$; $p < .01$).

The fact that my child has a handicapping condition has strained my marriage.

This statement, analyzed separately for one and two parent families, was crosstabulated by income. The statement itself was "not applicable" for 57% of the single parent respondents, and was a "very substantial" or "enormous" problem to 30% of them. In two parent families, significantly more respondents in the Medium income level reported marriage problems (40%, versus 20% in the High income group, and 32% in the sample as a whole;

chi-square = 9.00; 3df; $p < .03$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .32$; $p < .01$).

My lifestyle is different from what I expected it would be, because my child has a handicapping condition.

Mothers with at least some college called this a problem more frequently (54% versus 34%; chi-square = 7.00; 3df; $p < .07$) and with a higher Stress Rating (chi-square = 23.89; 15df; $p < .07$) than mothers with high school or less. Stress Ratings on this item were significantly correlated with Disability Scores ($r = .39$; $p < .01$).

I am concerned that my child might have difficulty developing self-confidence and self-esteem.

Sixty-one percent of college graduates, compared to 42% of high school graduates, said this was a problem (chi-square = 18.00; 3df; $p < .00$). The more educated mothers also tended to give this problem high Stress Ratings (chi-square = 43.36; 15df; $p < .01$).

I worry that I tend to overprotect my child.

The same patterns described above relating concern for the child and mother's education level were found in this statement. Mothers with less than high school educations were less likely to say this was a problem; mothers with some college were most likely to say this was a problem; (27% versus 60%; chi-square = 13.89; 3df; $p < .00$). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .18$; $p < .01$).

Mother's employment status was examined in the following survey item:

Working members of our family have not been able to work even when they wanted to, because of our situation caring for our child.

Families with incomes in the Low Medium range were least likely to say this was a problem (14%) whereas families in the Low income group were most likely to say this was a problem (30%; chi-square = 10.39; 3df; $p < .02$). Overall, 26% of unemployed mothers said that not being able to work, because of their situation caring for their handicapped child, was a problem. Thirty-three percent of single, unemployed mothers and 24% of married, unemployed mothers had this problem (66% of the married mothers and 66% of the single mothers, were not employed out of the home). Stress Ratings on this item were significantly correlated with Disability Scores ($r = .33$; $p < .01$).

Non-significant relationships. A number of factors were found to be unrelated to the kinds of problems and stresses covered by this survey. The child's age and sex, the family's size, and the degree of the family's religious involvement, were all unrelated to respondent's Problem Scores or Stress Ratings.

Discussion

The results of this survey reflect the stresses and concerns of families of young handicapped children who are receiving a range of services for their handicapping conditions. The following discussion of the results and implications of the survey is guided by the four original research questions. In general, findings support previous research in this field.

It is important to emphasize that 90% of the children were age 6 years and under, so that certain problems associated with older handicapped children were not found. The younger the child, the less likely the parents have been given a firm diagnosis of the child's condition or eventual functional disability. Many problems are not obvious when a child is young; during these years it is easier to physically handle a child and there is less obvious discrepancy from normal development if the child has not yet mastered certain self-help and communication skills. Parents would not yet be able to predict if they would need to make architectural changes to their homes, or set about finding an alternative living arrangement for the child as an adult. All of these reasons would contribute to the large number of "not applicable" ratings given on the survey statements. Indeed, many parents wrote in comments to this effect; e.g., "She's too little to apply to some questions yet," "...Cindy needs to be a little older before I know if some of these things become more of a problem."

The impact of the older handicapped child on the family has been studied less thoroughly than the impact of younger populations, and professionals tend to underestimate the severity of the effects on the family (Wikler et al., 1981). More research needs to be done in this area, especially as more older handicapped children are remaining with their families, instead of being transferred to institutions.

The severity of the child's disability was a significant predictor of both the number of problems families reported, and the Stress Rating they assigned to these problems. This relationship was found in every survey category, but was strongest for those categories which more directly reflected the experiences of the primary caregiver: Impact on Family, Emotional Impact on Caregiver, and Role Demands on Caregiver. Individual survey items which described problems directly affecting the primary caregiver, either in her role as caregiver, or in other aspects of her life, had the highest correlations with the child's Disability Score ($r = .32$ and above).

These results support findings reported in other studies (Korn et al., 1978; Nevin & McCubbin, 1979; Breslau, Staruch & Mortimer, 1982). In Breslau et al.'s study, this finding held even when mothers' education,

family income, and race were controlled. The reasons that the severity of a child's disability is associated with the number of problems and level of stress in a family are based on the real physical demands involved in caring for a disabled child. Mothers are generally responsible for the bulk of child care. It follows that they would directly experience the stresses of the "burden of care" involved in rearing a handicapped child. These stresses include time-consuming caregiving tasks, physically-demanding lifting and carrying, and the emotional drain that is the result of having too little time and energy for self, recreation, and relationships. This interpretation is supported by Breslau, Staruch & Mortimer (1982), who asked mothers to subjectively rate the extent to which the care of a disabled child restricted their non-familial roles such as being employed, continuing their education, following their own interests, and participating in activities outside the home. Role restriction was directly related to the child's dependence in daily activities (a measure of the severity of the child's disability). Also, the more restricted the mothers felt, the more maternal distress they experienced.

The impact of a single stressor, like child disability, is difficult to assess alone. It is best understood in the context of other ongoing events that may intensify or diminish the impact of that stressor. In this study, a number of factors were associated with higher and lower levels of reported impact, whatever the child's disability level.

In general, respondents in the High income group (over \$30,000) had fewer problems and lower stress ratings than the sample average, and respondents in the Low income group (below \$10,000) had more problems at higher Stress Ratings than the sample average. However, the Medium income group, families between \$20,000 and \$30,000, frequently had as high or higher problem and Stress Ratings as this lowest income group. There appeared to be two other factors which helped account for these results.

One of these factors is that Medium income families are frequently not eligible for services because their incomes are above a certain level. Many respondents wrote in comments to this effect:

*We are making it but losing ground. There will come a time,
I am sure, when our handicapped child will have to do without.*

One father wrote:

I think it is a shame the state helps people who have foster homes for these children and Social Security will pay, but they won't help the parents who want to keep and love their handicapped child. It seems as if we are being punished for keeping our children. There is no financial help unless you are on welfare or give your child up. Otherwise, the rest of the family does without.

Another mother appended a letter to her survey:

We have five kids, our house payment equals half of our monthly income, all our necessary bills such as P.U.D., phone, sewer, etc. keep going higher, not to mention the cost of food, clothing, and

transportation. Now with all the cuts in the different budgets we have been told our income is too high for our daughter to be covered fully by Crippled Children's Services. We would have had to come up with \$60-\$100 a month to keep this coverage. At this point we are going month by month through the March of Dimes to pay for her therapy, but I don't know if March of Dimes will cover any hospital costs if she gets sick again. She is just 2 years old and has had a total of seven major surgeries.

Another factor which would help explain the higher Stress Ratings in the Medium income group is that some areas were given higher Stress Ratings by mothers with more education, and education and income are correlated. Mothers with at least some college had higher Stress Ratings for the survey as a whole, and for Impact on the Family, and Emotional Impact on the Primary Caregiver. This finding seems to be somewhat contradictory, since education is theoretically a "coping resource" (McCubbin & Patterson, 1981). Breslau, Staruch and Mortimer (1982) found that maternal Depression-Anxiety decreased as income and education level rose. Korn et al. (1978) found a similar, non-significant trend. Other studies, however, have suggested that child disability is perceived differently by lower and higher socio-economic families. Parents with more education experience stress in terms of disappointed expectations for their child and themselves, whereas families with less education and income tend to focus on the caregiving demands and financial strains (Farber, 1960; Dunlap & Hollinsworth, 1977). This interpretation is supported by the finding in the present study that the more educated mothers expressed more concern for their handicapped child's emotional and social development. These mothers could be more sensitive to emotional problems that can arise when a child cannot perform as well as peers and siblings. These mothers may also be more aware of how their handicapped child is different from peers and siblings. The more educated mothers in this sample also reported feeling more depleted emotionally themselves, and tended to view as more stressful the fact that their lifestyles were different from what they had expected, because of their situation with their handicapped children. The question of how education affects mothers' perceptions of their situation certainly deserves more research, especially since these results differ somewhat from those reported by Breslau, Staruch and Mortimer (1982).

Two ways in which the mothers' lifestyles might have been affected were explored in more detail. Analyses of the statement concerning marital stress revealed that significantly more couples in the Medium income group (42%) reported marital strain because of their situation with their handicapped child. Least stressed was the High income group (22%). The fact that 30% of single mothers said that marital strain was a "very substantial" or "enormous" problem, suggests that having a disabled child contributed to the problems that caused at least some of these couples to separate. However, insufficient background information was collected to clarify this point. Definitions of marital distress vary widely, as do reported of the proportions of families with handicapped children who experience marital distress. Figures in the literature vary widely: 19% (D'Arcy, 1968); 25% (Korn et al., 1978); 39% (Blackard & Barsh, 1982a); 67% (Gath, 1977).

In our sample, one mother wrote in: "My handicapped child caused divorce;" another wrote in that her marriage was strained "very badly the first 18 months, now smoothing out nicely" (child was 3½ years); and another wrote "quite the contrary" beneath the statement. A disabled child may negatively affect an already strained marriage, and in other instances can cause a family to come closer together. Friedrich (1979), for instance, found that marital satisfaction was the single best predictor of a family's positive coping behavior with the situation of rearing a handicapped child. In the present study, it was not possible to determine if families with strong marriages reported less stress and more positive effects.

Maternal employment status was examined for one and two parent families, by income level. Not being able to work when they wanted to was a problem for 27% of single mothers and 21% of married mothers. However, proportionately more of the married mothers for whom this was a problem said they were "unemployed and looking" (54%); compared to single mothers "unemployed and looking" (30%) for whom not working was a problem. More married, unemployed mothers felt they had the option to work. Not being able to work was a problem for more of the Low income mothers (30%) and for fewer of the Low Medium income mothers (14%). In this sample, this was the income group that also had a highest proportion of mothers working part-time, 24%, compared to 11% in the under \$10,000 group. Part-time work may be the least stressful, most attractive alternative for mothers who want to work.

Breslau, Salkever and Staruch (1982) made the point that lower income wives are more likely to be in an either/or situation of having to choose between the conflicting demands of continued employment and caring for a disabled child in the home. They found that mothers from families with incomes below the median were less likely to work if they had a disabled child, than if they did not. Mothers from families with incomes above the median were more likely to work (especially part-time) if they had a disabled child, than if they did not. Breslau et al. did not report the proportion of mothers of disabled children below and above the median who were actually employed, so that their data cannot be compared with data from the present study. Contrary to Breslau et al., the present study did not find that significantly fewer mothers with lower family incomes worked (33%) than mothers with higher family incomes (36%), but did find that more unemployed, single mothers felt they did not have an option to work. This latter finding does conform to an either/or interpretation of work status.

The other side of this question--how many mothers must work when they would rather not, because of their situation with their child, showed that it was overall a problem for 14% of the sample, with no significant differences between income groups.

In this sample, then, there were mothers who were not working when they wanted to, because of child care demands, and others who were working when they did not want to, because of financial demands. Respondents wrote in some comments that help explain this situation:

I have to work part-time for insurance coverage...

I'm afraid to change occupations because there would be no insurance for the child...

I worry how I can get a job and take my child to therapy as well...

Caring for my child cut into the small amount of time I could spend at work, until my employer had to cut my hours back to less than half time...

We have to pay for his things that our income level prevents us from having--which means I have to work to pay for them.

The conflicting demands experienced by these mothers are not generally different in kind from those experienced by working mothers of non-handicapped children, but they are more severe and are likely to persist longer. There are also caregiving demands associated with handicapped children that parents of non-handicapped children do not have to face at all, such as dealing with special agencies and obtaining information and special services, e.g.:

I spend a great deal of time and effort filling our forms for related agencies when they could easily share the information...

There is no central resource that has all the current options to be available in the area, and a bit about each option available. A parent has to be a detective to find out what is best for one's child...

A lot of time is spent in simply getting services our child needs that are guaranteed by law.

In summary, the severity of the child's disability was highly related to the number and severity of the parents' problems. The primary caregiver experienced much of the impact of caring for the disabled child. Time demands and emotional strain were frequently cited, and the need for more respite was written in on many surveys:

No one will watch my child even for an hour. I need a break...

Adequate respite care is not available...

Insufficient respite was a problem for all kinds of families, even those that could afford to pay for it; there is a general shortage of trained respite providers and appropriate respite facilities (Blackard & Barsh, 1982a). The role restriction experienced by primary caregivers and on family activities in general, could be relieved if more respite were readily available (Simeonsson & Simeonsson, 1981).

Financial problems were experienced to some degree by all income groups, but in different ways. Many concerns were related to fear of budget cuts for existing services, or eligibility problems for middle income families. Although the parents of the more severely disabled children had more problems, a few parents of mildly involved children were also stressed, e.g., "I've found that many preschools are prejudiced against mildly handicapped children--

yet public education won't pay for the mildly handicapped, either." The number of families experiencing moderate or severe stress in any area was always a minority of the sample. Most parents were coping adequately and generally satisfied with their lives and the services their child was receiving. Blackard and Barsh (1982a) also found that fewer than half of their families reported negative changes resulting from their child's handicap. In that study, 30% reported a change in family goals as a result of a child's handicap.

In the present study, the average respondent had an average Stress Rating between 1 and 2 (between "This situation is little or no problem," and "This situation is somewhat of a problem."). Nevertheless, there were some individuals who were experiencing a higher intensity of problems. Across respondents, 21% of the item ratings were represented as "rather important, very substantial, or enormous" problems. These families were troubled despite the fact that they were already involved in the service system for themselves and their children.

This last conclusion has several important implications for the design of a program to alleviate negative impact on families of handicapped children. The parents generally did not need additional formal services for themselves and their children. They needed help coping with and fully utilizing existing services, and they needed some relief from the daily burden of care. The Extending Family Resources Project was designed to help in both these areas by expanding the family's social support network. Extended family members helped parents deal with the system, for instance, by providing transportation or babysitting to make using services easier, and they personally assumed some of the physical aspects of caregiving so that the parents could get an occasional break. Finally, the Extending Family Resources Project fostered flexible coping styles and problem-solving abilities; families learned that they could continue to use social supports effectively as new problem areas appeared.

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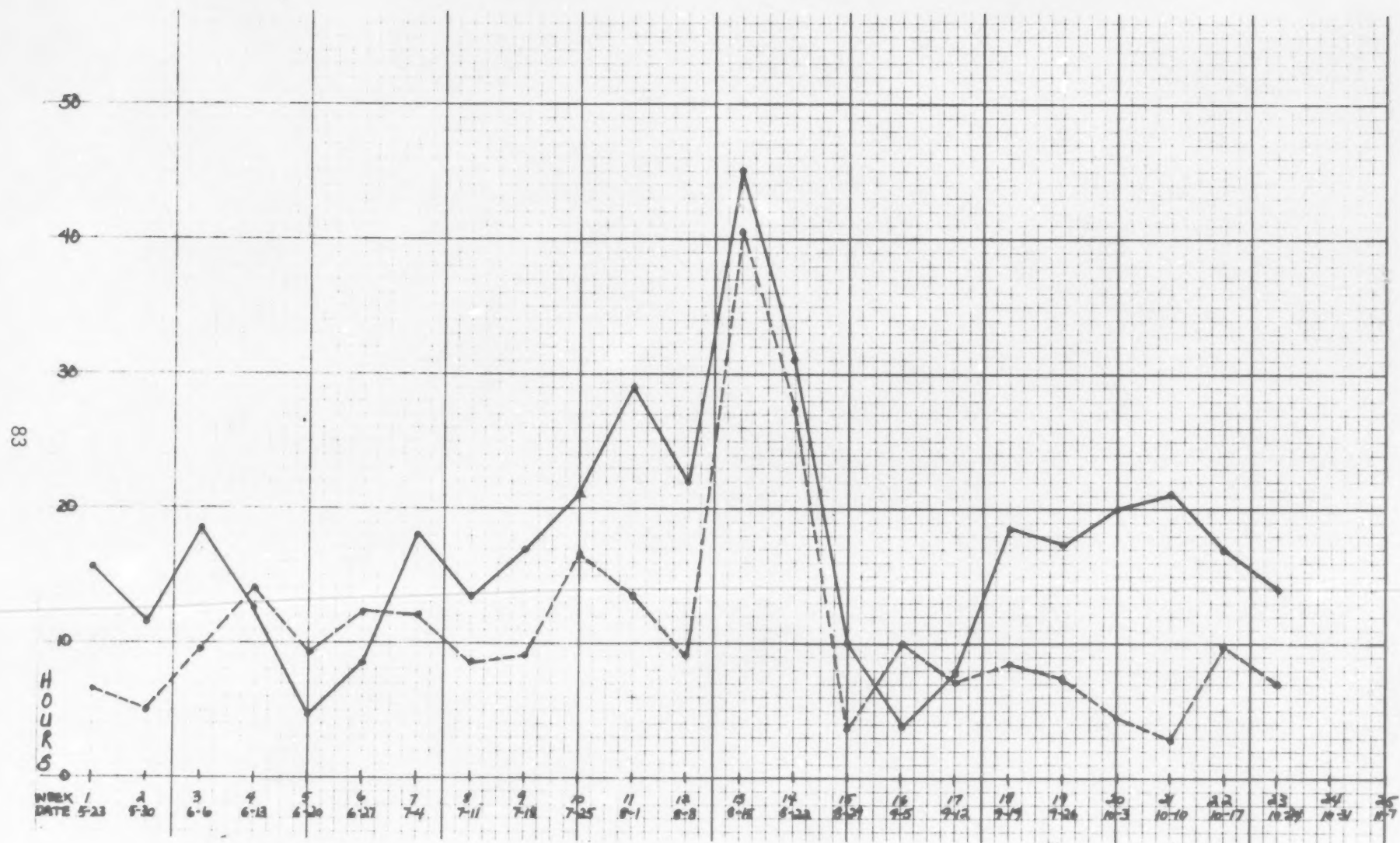
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Appendix A

Representative Graph of Daily Log Data



Respite hours

Combined hours: couple and other child

Appendix B

Survey for Parents of Children with Handicapping Conditions



A SURVEY FOR PARENTS OF CHILDREN WITH HANDICAPPING CONDITIONS

Below is a list of problems and concerns that are sometimes expressed by parents of children with handicapping conditions. While not everyone has the same experiences, we would like to know whether you have had these problems and concerns, and the extent to which a particular problem made it difficult to meet the needs of your child, yourself, and other family members. If you have more than one handicapped child, please answer the survey in terms of the oldest. If this list does not include experiences you have had, please add them on the blank lines at the end of each section. All information related to this survey will be completely confidential.

Read each sentence. If the item does not apply to your situation, circle NA (for not applicable) and move on to the next line. Otherwise, circle the number that best describes how that situation affected you:

- NA This situation is not applicable to me or my family
- 1 This situation is little or no problem
- 2 This situation is somewhat of a problem
- 3 This situation is a rather important problem
- 4 This situation is a very substantial problem
- 5 This situation is an enormous problem

1. FINANCES

- | | | | | | | |
|---|----|---|---|---|---|---|
| 1. Because of my child's handicapping condition, I must buy more expensive toys, clothing, and equipment for her/him, than I otherwise would choose to buy. | NA | 1 | 2 | 3 | 4 | 5 |
| 2. I cannot afford the special education that I want my child to have. | NA | 1 | 2 | 3 | 4 | 5 |
| 3. I worry that at any time our insurance company will drop the benefits needed to pay for services for my child. | NA | 1 | 2 | 3 | 4 | 5 |
| 4. I cannot afford the special therapy my child needs. | NA | 1 | 2 | 3 | 4 | 5 |
| 5. I could not afford an alternative living arrangement for my child. | NA | 1 | 2 | 3 | 4 | 5 |
| 6. I cannot afford special equipment my child needs (e.g. wedge, prone board, electric wheelchair). | NA | 1 | 2 | 3 | 4 | 5 |
| 7. I worry that I have not changed my will (or do not have a will) to plan for my child's financial security. | NA | 1 | 2 | 3 | 4 | 5 |
| 8. Because of my child's disability, I have had to (or will have to) make expensive changes in our house or apartment. | NA | 1 | 2 | 3 | 4 | 5 |
| 9. I worry that I/we will not ever be able to retire. | NA | 1 | 2 | 3 | 4 | 5 |
| 10. Some months, it comes to a choice between paying bills related to my child's disability, or buying groceries. | NA | 1 | 2 | 3 | 4 | 5 |
| 11. Because the expenses related to my child's disability keep increasing, I just feel my family will never get ahead. | NA | 1 | 2 | 3 | 4 | 5 |
| 12. I cannot afford enough child/respite care to get a break as often as I would like. | NA | 1 | 2 | 3 | 4 | 5 |
| Other | NA | 1 | 2 | 3 | 4 | 5 |

2. OBTAINING INFORMATION

- | | | | | | | |
|--|----|---|---|---|---|---|
| 13. It has been difficult to obtain information on what services are available to my child. | NA | 1 | 2 | 3 | 4 | 5 |
| 14. I always seem to find out about services for me or my child when it is too late to make use of them. | NA | 1 | 2 | 3 | 4 | 5 |

15. I would like to take some parent training or parent education courses, but without a babysitter, or transportation, it is impossible.	NA	1	2	3	4
16. I cannot tell if my child's education is as good as it should be.	NA	1	2	3	4
17. I cannot tell if my child's therapy is as good as it should be.	NA	1	2	3	4
18. I need information on how to handle and care for my child at home.	NA	1	2	3	4
19. I need information on managing my child's behavior problems.	NA	1	2	3	4
Other	NA	1	2	3	4
3. COMMUNICATING WITH PROFESSIONALS					
20. My child's doctors do not believe me when I tell them my child has a problem.	NA	1	2	3	4
21. The doctors or therapists treating my child have not talked to me in words that I can understand.	NA	1	2	3	4
22. When I try to seek help for my child I get the "run around" from the bureaucrats in human service agencies.	NA	1	2	3	4
23. I have questions about my child's disability and treatment that have not been answered to my satisfaction by the therapists or doctors seeing my child.	NA	1	2	3	4
24. I often have long waits at my child's doctor appointments.	NA	1	2	3	4
Other	NA	1	2	3	4
4. ELIGIBILITY					
25. Because our income is above a certain level, we are not eligible for certain services that we really do need.	NA	1	2	3	4
26. My child's particular disability does not meet the eligibility requirements for services I think he/she should be getting.	NA	1	2	3	4
Other	NA	1	2	3	4
5. AVAILABILITY OF SERVICES					
27. My child's therapist does not appear to have the training that would best help my child.	NA	1	2	3	4
28. My child is not receiving as much therapy as he/she needs.	NA	1	2	3	4
29. The public schools are not providing the education that my child is entitled to under the law.	NA	1	2	3	4
30. I cannot find a program that offers the kinds of social experiences that my child needs.	NA	1	2	3	4
31. The services that I would like for my child are located a long distance from where I live.	NA	1	2	3	4
32. My child has had to change teachers or therapists frequently, and this has resulted in delays in her/his program.	NA	1	2	3	4
33. Transportation for my child to and from appointments and school is not provided.	NA	1	2	3	4
34. There are too few recreational opportunities for handicapped children in our area.	NA	1	2	3	4

35. It is hard to find a babysitter for my handicapped child.	NA	1	2	3	4	5
36. Finding an appropriate alternative living arrangement for our child, such as a group home, is (would be) difficult.	NA	1	2	3	4	5
Other	NA	1	2	3	4	5

6. COMMUNITY ATTITUDES

37. I have a hard time explaining my child's disability to friends and relatives.	NA	1	2	3	4	5
38. Public places, like department stores, are just not designed so that I can conveniently bring my child with me.	NA	1	2	3	4	5
39. I am disturbed by the lack of knowledge and the rudeness or intrusiveness of many of the people my child and I meet.	NA	1	2	3	4	5
40. I get angry when people park their cars in parking places reserved for cars with handicap license plates.	NA	1	2	3	4	5
41. I worry whether my child will be accepted by his/her peers and the community.	NA	1	2	3	4	5
42. My child gets teased by other children.	NA	1	2	3	4	5
43. Others find it hard to get along with my child because of his/her appearance or behavior.	NA	1	2	3	4	5
Other	NA	1	2	3	4	5

7. TIME

44. It takes so much time to care for my child that I have little or no time for myself.	NA	1	2	3	4	5
45. It takes so much time to care for my child that I have little time to spend with my spouse or friend.	NA	1	2	3	4	5
46. My child generally only lets one person hold and care for him/her, so that person rarely gets a break from child care tasks.	NA	1	2	3	4	5
47. I spend a great deal of time every week transporting my child to school and/or appointments.	NA	1	2	3	4	5
48. It is difficult to keep my child happily occupied.	NA	1	2	3	4	5
49. I cannot seem to get routine family chores done.	NA	1	2	3	4	5
Other	NA	1	2	3	4	5

8. IMPACT ON PRIMARY CAREGIVER

50. One hard thing to accept about raising a child with a developmental disability is that I will be doing certain caretaking tasks for much longer than I had expected.	NA	1	2	3	4	5
51. Emotionally, it is hard to accept that I may not always be able to care for my child at home.	NA	1	2	3	4	5
52. Sometimes I feel powerless to help my child.	NA	1	2	3	4	5
53. It is not easy for me to talk to my child about his/her handicapping condition.	NA	1	2	3	4	5
54. I worry that I am not doing as good a job taking care of my child as I could be.	NA	1	2	3	4	5

55. I am personally sick and tired of having to struggle, complain and fight so that my child can get the services to which he/she is entitled.	NA	1	2	3	4	5
56. Because of the demands of caring for a handicapped child, I have little emotional energy to deal with other areas of my life.	NA	1	2	3	4	5
Other	NA	1	2	3	4	5

9. LIMITS ON LIFESTYLE OR LIFE CHOICES

57. As a family we feel isolated from our former friends and contacts in the community.	NA	1	2	3	4	5
58. Socially, I rarely get together with parents who do <u>not</u> have a child with a handicapping condition.	NA	1	2	3	4	5
59. My lifestyle is different from what it <u>was</u> because my child has a handicapping condition.	NA	1	2	3	4	5
60. My lifestyle is different from what I expected it <u>would be</u> because my child has a handicapping condition.	NA	1	2	3	4	5
61. Working members of our family have not been able to work, even though they wanted to, because of our situation caring for our child.	NA	1	2	3	4	5
62. Working members of our family have had to take jobs that they otherwise would not have wanted, because of our situation caring for our child.	NA	1	2	3	4	5
63. A member of our family has not been able to continue with his/her education, because of the extra demands of caring for our child.	NA	1	2	3	4	5
64. I have had to decide where to live on the basis of my child's needs for special services. These services are not available in the area I would like.	NA	1	2	3	4	5
65. Because of my child's disability I have a limited choice concerning the design of houses or apartments in which we can live.	NA	1	2	3	4	5
Other	NA	1	2	3	4	5

10. IMPACT ON FAMILY

66. The fact that my child has a handicapping condition has strained my marriage.	NA	1	2	3	4	5
67. My spouse and I disagree on what is best for my child.	NA	1	2	3	4	5
68. My relatives cannot or do not help me with my handicapped child.	NA	1	2	3	4	5
69. My child's grandparents are not as accepting of my child as they would probably be if my child did not have a handicapping condition.	NA	1	2	3	4	5
70. My other children do not get as much of my time and attention as I would like them to have.	NA	1	2	3	4	5
71. My other children have developed behavioral and personal problems as a result of living with their sister or brother who has a handicapping condition.	NA	1	2	3	4	5
72. I worry that I tend to overprotect my handicapped child.	NA	1	2	3	4	5
73. I worry about my child's vulnerability to sexual exploitation.	NA	1	2	3	4	5
74. I am concerned that my child might have difficulty developing self-confidence and self-esteem.	NA	1	2	3	4	5
75. There is so much concern for my child's developmental disability, that I worry that she/he does not have a chance to be "just a kid."	NA	1	2	3	4	5
Other	NA	1	2	3	4	5

THANK YOU!!